In-Home Pediatric Care: Children Need It and the Law Requires It
Sessions # 13035/14023
Section on Home Care, AAP
National Health Law Program

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Disclosure of Relevant Financial Relationships:
In the past 12 months, I have had the following financial relationships to disclose:

Consultant for:    Integrity Health Care

Speaker name:  Jane Perkins, J.D. MPH  I have no financial relationships to disclose.

Disclosure of Off-Label and/or investigative uses:
We will not discuss off label use and/or investigational use in this presentation
PEDIATRIC in Home Health Care

- Why is it important to pediatricians?
- Why are the EPSDT MANDATES important?
- Why is it important to patients and families?
- What services does EPSDT cover?
- How do we access services and funding sources?
- How do I advocate for services in my state?
This is what happens
when your children take away your driver’s license
Pediatric Home Health Care
Pediatric Home Health Care
Pediatric Home Health Care
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
Pediatric Home Health Care

- **History**
  - Home health care was the fastest growing division of personal health care spending in the early 1990’s.
  - The Centers for Medicare and Medicaid Administrator designated pediatrics as the fastest growing segment within home health care.
Pediatric Home Health Care

- The American Academy of Pediatrics has created the Section on Home Care

- The AAP publishes: GUIDELINES FOR PEDIATRIC HOME HEALTH

  - Reference based on best practices
  - “Home care is an integral and essential part of the medical home that we advocate for every child.” (Editors)

Reference: GUIDELINES FOR PEDIATRIC HOME HEALTH CARE, 2nd edition AAP
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/tracheostomy tubes
Increased number of premature infants with associated respiratory, cardiac, and feeding problems

- More than 40% of extremely small <800 gms and premature infants <26 weeks 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
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, \textit{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 & Medicaid Services)

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 our patients and their families
Medicaid’s Federal child health program for youth 0 to 21 years old:

- **Federal Law** defines very comprehensive benefits different from adults.
- **State-specific financial eligibility criteria for entry**
- Goal: Identify early, access TX and monitoring so “handicaps do not go neglected”

**Five screens required at specific intervals AND when problems:**

- Physical and Mental Health, Vision, Hearing, and Dental
- Performed by Health Care Professional
Medicaid rules are different for children 0 to 21

- Covers the *full range* of Health Care and Long Term Care Services and Supports

- **Under Federal law**, States are required to cover services and supports under EPSDT *regardless of whether coverage for the same service/support is an optional or limited service for adults under the state plan.*

- Under Federal law, EPSDT programs are required to provide all necessary services to “**correct or ameliorate** physical and mental illnesses and conditions” discovered by routine screening.
Services need not cure to be covered

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.
The EPSDT Benefits

- Physician services
- Hospital services *(outpatient and inpatient)*
- Federally 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 health care**
  - **Private duty nursing services**
  - **Personal care services**
  - **Dental Services**
  - **Physical, Occupational, and Speech Therapy**
- Prescribed medications
- 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 (e.g., transportation)
**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)
“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

Uneven access to services comes from state-specific variability in program implementation and interpretation of federal law.
EPSDT - A Guide for States:
Coverage in the Medicaid Benefit for Children and Adolescents

Early and Periodic Screening, Diagnostic and Treatment (EPSDT)

JUNE 2014

Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html
Why is Home Care Important to Families?
When my child was born, they offered NO kind of information for special nursing. They threw me out blinded with fear. The only thing I was made aware of was PT-Steps. Which is a therapist for PT, OT, Vision, Nutrition. They (the children) receive this only until the age of 2. My PT therapist had to lead me in the right direction. She could not understand why one little girl she saw as 10 cent was better than my daughter I received nursing. I told her that I had no clue what she was talking about. She then in turn got the who needed and I then called who is now my child manager. My point 2: Someone needs to get this info out there for parents, Guardians, whoever. We need this information like I said above was given to me. I took care of my daughter full-time. By myself I did this for 1-1/2 years with NO help from anyone. NO family, friends...NOTHING. By the grace of GOD my PT gave me that info. I was close to suicide. I am now proud to be a full-time college student with a 3.04 GPA. This info cannot be held back. It is vital & crucial for EVERYONE involved.

Thank you!
NOT HOME:

A DOCUMENTARY ABOUT KIDS LIVING IN NURSING FACILITIES

A film by: Narcel G. Reedus
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)
Stressors Cont.

- **Financial Strain**
  - **Limitation of employment**
    - 54% reported that a family member stopped working because of the child’s health
    - 45% reported that a family member cut back on working hours to care for child
      (Kuo and Cohen, Arch Pediatr Adolesc Med/Vol 165 (No. 11) Nov 2011.)
  - 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
    (Porterfield and Derigne, Pediatrics 2011:1128:892)
  - >20% of families raising a CSHCN report financial problems attributed to their child’s condition (Porterfield and Derigne)
• 58% of parents/caregivers report spending more than 40 hours per week providing support for their loved one with I/DD, including 40% spending more than 80 hours a week.

• Nearly half (46%) of parents/caregivers report that they have more caregiving responsibilities than they can handle.

• The vast majority of caregivers report that they are suffering from physical fatigue (88%), emotional stress (81%) and emotional upset or guilt (81%) some or most of the time.

"Still In The Shadows With Their Future Uncertain"
www.thearc.org/document.doc?id=3672
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, ventilators, apnea monitors, and oxygen
  - Shift 1-4 hours
Private Duty Nursing

- Complex nursing care for a patient with a more 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/EPSDT standards will determine services
Private Duty Nursing

- **Duties**
  - Medications-IV,IM,PO
  - Parental 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
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 gastrostomy tube may spend up to 8 hours per day on care activities, compared with 3 hours for children without gastrostomy tubes. Parents of children with gastrostomy tubes also experience higher out-of-pocket expenses for their child when compared to children without gastrostomy 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/EPSDT standards

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 encopresis 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)
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.

“Historically the service has been utilized by few children”

Reference: The MO HealthNet Personal Care Manual, Section 13.10
When there is no documented medical need for care

For cases that require skilled nursing-level services only.

The family needs:
- Respite or baby-sitting services
- Homemaker-only service
Personal Care Aide

Case where personal care assistance is appropriate.

A 13-year-old who uses a wheel-chair needs assistance with breakfast and getting ready for school.

- Parent must leave for work at 6:30 in the morning, too early to get the child ready for the bus.

- Because ADLs for a typically developing 13 year-old include the ability to make his own breakfast, get dressed for school, and be waiting for the bus independently; personal care assistance is appropriate with a care plan specific to his needs.
A 15-year-old child with significant motor and/or neurocognitive/behavioral impairments who weighs 150 lbs.

- 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 in the family home.

Personal care assistance is appropriate for this youth with a care plan specific to his needs.
5 year-old child needs personal care due to a medical condition.

- **Parent has four children, ages 5 and under.**
  - The other three children have no medical problems.
  - **Parent is available in the home.**
  - If the child were an only child, personal care is questionable, in spite of the disability, because of the availability of the parent.

The needs of the 3 additional young children render the parent unavailable to meet the extra personal care needs of the child with disabilities.
Personal Care Aide
Clients by Diagnosis

- **Total: 50**
- **Muscular Dystrophy: 6**
- **Autism: 9**
  (1 Down Syndrome, 1 Shaken Baby Syndrome)
- Rett Syndrome: 1
- Rohhad’s Disorder: 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
Nursing and Personal Care Aide
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Survey Results for *Personal Care Aide*

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<td>BSHCN</td>
<td>+</td>
<td>Infant</td>
<td>MR/Chromosomal Duplication</td>
</tr>
<tr>
<td>16 years</td>
<td>Friend</td>
<td>+</td>
<td>10 months</td>
<td>Trisomy 8p</td>
</tr>
<tr>
<td>9 years</td>
<td>Hospital</td>
<td>+</td>
<td>Birth</td>
<td>MR/CP</td>
</tr>
</tbody>
</table>
### Survey: Home Health Care Referral—Referral Source, age, delay in referral

<table>
<thead>
<tr>
<th>Personal Care Aide</th>
<th>Private Duty Nursing</th>
</tr>
</thead>
<tbody>
<tr>
<td>✦ 1/8 referred by doctor</td>
<td>✦ 8/42 patients referred by doctor</td>
</tr>
<tr>
<td>✦ 1/8 referred by hospital</td>
<td>✦ 3/42 patients referred by Dr/hospital</td>
</tr>
<tr>
<td>✦ 10/42 patients referred by hospital</td>
<td>✦ 10/42 patients referred by hospital</td>
</tr>
<tr>
<td>✦ 6/42 referred by parent</td>
<td>✦ 6/42 referred by parent</td>
</tr>
</tbody>
</table>

Range in age at referral 0-16 yrs.  
Mean delay from Dx~7 yrs.  

Range in age at referral 0-17 yrs.  
Mean delay from Dx~6 yrs.  

### Conclusions
- Significant delays between dx. and referral for home health services  
- Majority of referrals do not currently involve doctors or therapists  
- ..........WE can prevent that delay
CHANGES YOU MAY WISH TO MAKE IN YOUR PRACTICE

1) Assess each patient with a cognitive and or physical disability regarding the need for in home services

2) Assist them in accessing services

3) Advocate for HOME BASED SERVICES in your state
Advocating for EPSDT in-home services: What pediatricians can do

- Seek coverage for individual patients
- Help address systemic problems & improve the benefit
Do the health care needs of your patient fit within the scope of benefits?

<table>
<thead>
<tr>
<th>Mandatory services</th>
<th>Optional Services (for adults)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician services</td>
<td>Prescription drugs</td>
</tr>
<tr>
<td>Laboratory/x-ray</td>
<td>Dental services</td>
</tr>
<tr>
<td>In-patient hospital</td>
<td>Physical &amp; other therapies</td>
</tr>
<tr>
<td>Outpatient hospital</td>
<td>Private duty nursing</td>
</tr>
<tr>
<td>Home health care*</td>
<td>Home health care*</td>
</tr>
<tr>
<td>Nursing facility services</td>
<td>Rehabilitative services</td>
</tr>
<tr>
<td>EPSDT</td>
<td></td>
</tr>
</tbody>
</table>

Not covered: respite, home modifications, habilitative services
Are the health care needs of your patient medically necessary under EPSDT?

- Will the health care, treatment or other measures
  - Correct or ameliorate the patient’s condition?
EPSDT = Easy …1,2,3
A written request that includes:

- The physician’s prescription/orders on a claim/EPSDT Screen form
- Include justification from physician & other providers, including:
  - Patient history, including past Tx/services
  - Include role of caregiver, including their history of caregiving
  - Diagnosis/prognosis
  - Description of benefits being requested
  - Length of time the service/Tx is needed
When appropriate, include product information on:
- How an item will meet the child’s need
- Photographs/videos illustrating use

Note: “These services are being requested under the Medicaid EPSDT benefit to correct or ameliorate my patient’s physical/mental conditions.”
A word about Medicaid managed care

When State Medicaid agencies contract with at-risk health plans to provide Medicaid services

- EPSDT CANNOT BE IGNORED
- EPSDT STILL APPLIES
When Necessary Services are denied for children covered by EPSDT Medicaid

- **Written denial, giving factual & legal basis for action, explaining right to appeal & to continued benefits**
- (if available) Request peer-to-peer review by person with specialty background
- **Advise caregiver to file an administrative appeal**
  - Medicaid managed care – may require in-plan exhaustion
  - For urgently needed care, request an expedited appeal
  - Administrative fair hearing before state agency
  - Appeal to state court
- **Advise caregiver to seek legal assistance, e.g. legal services, disability rights, medical-legal partnership (contact info. on resource slide, *infra.*)**
Enrollees and providers also address systemic EPSDT problems

A WORD ABOUT:

Armstrong v. Exceptional Child Center
Supreme Court 2015

Next steps…..
Enrollees and providers also address systemic EPSDT problems, e.g.

- **Chisholm v. Hood** (La): community-based psychology services
- **K.G. v. Dudek** (Fla.): Applied Behavioral Analysis Therapy
- **Salazar v. D.C.** (D.C.): clinical guidelines for Medicaid in-home services
- **T.R. v. Dreyfus** (Wash.): intensive community-based services for children in juvenile/institutional settings
Enrollees and providers also address systemic EPSDT problems (con’t)

- *Katie A. v. Douglas* (Cal.): wraparound services and therapeutic foster care
- *Moore v. Reese* (Ga.): provider & state have role to play in deciding coverage
- *Pashby v. Cansler* (NC): Americans with Disabilities Act case requiring Medicaid coverage of in-home personal care services
Medicaid pathways to EPSDT home health coverage
Additional Coverage Pathways Home based Care

- **Children’s Health Insurance Program (CHIP)**—coverage based on “benchmark plans,” varies by state
- **Private Insurance**—coverage based on ACA and insurer policies, varies by state
  - ACA coverage based on “benchmark plans”
  - ACA coverage based on Essential Health Benefits (EHBs).
    - $EHB \neq EPSDT$
References

- Physicians often unaware that Medicaid patients qualify for home care services,  
  http://aapnews.aappublications.org/content/35/1/1.3
- TEFRA/Katie Beckett Option: http://www.hdwg.org/catalyst/cover-more-kids/tefra
- GUIDELINES FOR PEDIATRIC HOME HEALTH CARE 2nd edition, American Academy of Pediatrics
- Legal aid: http://www.lsc.gov
- Protection and Advocacy System: http://www.acl.gov/Programs/AIDD/Programs/PA/Contacts.aspx
- Medical-Legal Partnership:  http://medical-legalpartnership.org/
- States ranking on outcomes for individuals with ID/DD:  
  http://cfi2014.ucp.org/
- Not Home, Kids Living in Nursing Facilities, Documentary Film by Narcel G Reedus  www.nothomedocumentary.com
Thank you!