Coordination of Primary and Specialty Care for Uninsured Children with Complex Medical Conditions

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Disclosures

- **The speakers have no relevant financial interests to disclose.**

Objectives

- **Identify barriers to care of the uninsured child with complex medical needs**
- **Recognize community and governmental services available to assist with securing medical coverage for the uninsured child**
- **Describe practical tools for collaboration between pediatric subspecialties and primary care/general pediatrics**

Initial Encounters

- **Aaron is a 2 year old boy with Hemoglobin SS who immigrated to the US from Ghana with his mother**
- **First encounter with the US medical system was an ED visit for fever and splenic sequestration**
- **Medical barriers**
  - Genotype unknown
  - Immunization status unknown
  - Urgent pRBC transfusion without prior medical records
  - No PCP
- **Psychosocial barriers**
  - Undocumented
  - Lack of transportation/car seats
  - Lack of telephone
  - Mother is a single caregiver with multiple children

Understanding Residential Terms

- **US Citizens-*defined as*** being born in the United States or certain territories or outlying properties of the United States

or

- had a parent or parents who were citizens at the time of your birth

To become a citizen after birth, you must:

- Apply for “derived” or “acquired” citizenship through parents
- Apply for Naturalization

https://www.uscis.gov/us-citizenship

Understanding Residential Terms

- **Refugees *are defined as*** "someone who has been forced to flee his or her country because of persecution, war or violence. A refugee has a well-founded fear of persecution for reasons of race, religion, nationality, political opinion or membership in a particular social group. Most likely, they cannot return home or are afraid to do so. War and ethnic, tribal and religious violence are leading causes of refugees fleeing their countries."

https://www.unrefugees.org/refugee-facts/what-is-a-refugee/

Understanding Residential Terms

- **Undocumented Immigrants *are defined as*** a person who "entered the United States illegally without the proper authorization and documents, or who entered the United States legally and has since violated the terms of his or her visa or overstayed the time limit. An undocumented alien is deportable if apprehended."

- **Documented Immigrants *are defined as*** a person who "has been granted the right by the USCIS to reside permanently in the United States and to work without restrictions in the United States. Such an individual is also known known as a Lawful Permanent Resident (LPR)."

https://www.irs.gov/individuals/international-taxpayers/immigration-terms-and-definitions-involving-aliens

Citizenship Status and Insurance Options

US Citizens

- Commercial insurance
- Medicare
- Medicaid
- Marketplace

VS

Undocumented Immigrants

- Emergency Medicaid Services (in IN does not cover labs or routine care)
- Charity care/financial assistance through hospitals/medical offices

Initial Encounters

- **Outpatient clinics (primary care, general pediatrics offices)**
- **Federally Qualified Health Centers**
- **Emergency departments**
  - Children who lack a medical home may be higher utilizers of EDs
- **Community-based organizations**
- **Schools**

Common Needs

- **General pediatric care**
  - Immunizations, childhood development, acute needs unrelated to underlying diagnosis
- **Subspecialty care**
  - May require input from multiple subspecialists
  - Often only available at large centers, urban areas
- **Medications**
  - Compounding or delivery may be required
- **Laboratory monitoring/baseline function testing/routine imaging**

Complicating Factors for People with Chronic Health Conditions

Lack/Cost of Insurance:

- Study surveyed children with chronic health conditions, living in poverty are 118% more likely to be uninsured
- The Census found that 8.5% of the U.S. population went without medical insurance for all of 2018
- Many of those losing coverage were non-citizens
- Families with insurance still have out-of-pocket costs including co-pays, premiums, and deductibles which can be a barrier for medical treatment in low income households

Newacheck, P. W. (1994). Poverty and Childhood Illnesses. *JAMA Pediatrics*.
https://khn.org/news/number-of-americans-without-insurance-rises-in-2018/

Subsequent Encounters

- **Aaron was transported to the ED again 1 month later via EMS after a home visit with SCD coordinator and social worker**
  - Fatigue, splenomegaly, respiratory distress
  - Hb 3.4 g/dL
- **Medical barriers**
  - Need for ongoing lab checks
  - Cannot afford prescriptions
  - No PCP
- **Psychosocial barriers**
  - Disconnected telephone
  - New pregnancy, emotional stress
  - Extended family resistance to splenectomy

Complicating Factors for People with Chronic Health Conditions

- Language (lack of interpretation services)
- Immigration status-may not be comfortable applying for specific programs
- Literacy barriers
- Cultural views
- Low health literacy
- Written communication not in plain language
- Lack of financial stability

Schyve, P. M. (2007). Language Differences as a Barrier to Quality and Safety in Health Care: The Joint Commission Perspective. *Journal of General Internal Medicine*, *22*(S2), 360–361. doi: 10.1007/s11606-007-0365-3

Complicating Factors for People with Chronic Health Conditions

Transportation

- Lack of insurance that covers transportation
- Transportation services not reliable (e.g. Medicaid cabs)
- Lack of family support for medical appointments
- Public transportation/bus routes not in rural areas

Complicating Factors for People with Chronic Health Conditions

Maslow's Hierarchy of Needs

- Not the most important concern in their life

Establishment of Care

- **Aaron established care with a local primary care center**
  - Social workers helped to enroll in a financial assistance program
- **Medical barriers**
  - Poverty continued to limit access to recommended medications and screenings
- **Psychosocial barriers**
  - Mother’s roommate refused to provide a letter of support for charity coverage

Optimizing the Initial Medical Encounter

- **If possible, plan for an extended visit.**
  - Consider the possibility of negative medical encounters in the past
- **Reduce language barriers**
  - Determine which languages(s)/dialects are spoken
  - Assess literacy
  - Use medical interpreter assistance as needed
- **Identify the family's primary decision maker**
- **Identify financial barriers**
- **Involve multidisciplinary team**
  - Social work, educators

Subsequent Encounters

- **Aaron was again admitted with splenic sequestration**
- **The hospital social worker expedited his charity care application.**
- **Aaron’s extended family in Ghana agreed to have a splenectomy performed.**
- **A surgeon from another facility agreed to perform a pro bono elective surgery at the hospital where Aaron had secured charity medical coverage.**

Access to Care

- **Now 2 ½ years after his initial encounter with the US healthcare system, Aaron has active Medicaid.**

Coordination of Care

- 2 different charity care programs within 2 different healthcare organizations
- Emergency Medicaid
- Establishment with a local pediatrician at a primary care center
  - Pediatrician held regular care conferences with the primary care team and hematology
- Free penicillin through a state program
- Assistance with Medicaid cabs
- Supplies through the BABE program
- Anonymous donations of food, toiletries, clothes, and school supplies from staff

Solutions to Complicating Factors

- If transportation is a barrier, find local pharmacies that can deliver medications
- Talk to families about the importance of applying for charity care/financial assistance when applicable
- Collaborate with medical providers
- Educate families about the importance of treatment for their chronic health condition
- Some schools have school-based health clinics that offer free hearing tests and vision screenings, as well as provide flu vaccines

https://www.hrsa.gov/our-stories/school-health-centers/index.html

Solutions, Continued

- **Inter-organizational collaboration to maximize health benefits**
- **Scheduled care conferences**
- **Creative thinking**
  - Labs
  - Medication dosing
  - Appointment scheduling
- **Recurrent re-evaluation of status**
  - Continue to identify barriers (they may change!)

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