

Renovating Healthcare at Home for Children with Disability: Lessons from the Pandemic

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Caring for Our Children

Pediatric Home Health Care

- Medically essential care delivered at home for children with disabilities and complex chronic conditions

Services

- Private duty nursing
- Home health aide/personal care aide



Supplies & Equipment

- Mechanical ventilation, intravenous treatment, feeding equipment
- Home modifications to move within and out of home



Caring for Our Children

Pediatric Home Health Care

- 1 in 20 children are discharged from US hospitals to home care¹
- 1 in 20 of home health patients in US are children²
- 1 in 5 discharged home with care service or supply; 1 in 50 private duty nurse³

Example Patient Needs

Infant girl born very premature

- Private duty nurse for home breathing machine (ventilator), feeding tube and pump, medical monitoring equipment, reinforced electrical outlets

Teenage boy with muscular dystrophy

- Aide for activities of daily living, mobility and transfer equipment, medical bed, home ramp

Pandemic Revelations

1. Home Care as Integrated Health Care

2. Home Care as Secure Employment

3. Home Care as Measured Care

1. Home Care as Integrated Health Care

Challenges

Home care separation from most pediatric health systems more evident
Privilege and credentialing processes onerous across fractured market

Opportunities and Solutions

Integrate

Support alignment care across settings

- Lower or subsidize cost of electronic health record integration
- Incentivize shift to value-based care
 - Will encourage integration and lower medical error rate

Simplify

Centralize privilege and credentialing processes

- Will decrease barriers to entry for nurses
- May increase pool available to given family

2. Home Care As Secure Employment

Challenges

Cannot retain nurse when patient is hospitalized (Medicaid restriction)

Children cannot access school-related personal care services in remote school

Home nursing shortage worsened with pandemic pay raises in hospitals

Opportunities and Solutions

Payment Flexibility

Allow Medicaid overtime pay and pay while hospitalize for given period

Allow services workers at home during school hour if remote

Extend to non-licensed family caregivers

- Retains employees (minimize turnover)
- Reduce family financial strain or poverty

Competitive pay

- Rate increase commiserate with comparable hospital-skilled job
- Include mandatory pass through to home providers

3. Home Care As Measured Care

Challenges

Inability to identify & track children with disabilities

Lack of measures to compare and track care

Opportunities and Solutions

Develop Metrics (Federal)

CMS Medicaid Funded Home and Community-Based Services (HCBS)

- Financial and logistical commitment to develop pediatric HCBS metrics
 - Measures to support value-based care

Track Care (Federal/State)

- Develop system for monitoring population
- Engage pediatric experts and patient-families in quality/access boards
 - Ensure care is happening that is patient-family centered

Summary

1. Home Care As Integrated Health Care

- Support integration of care across settings
- Simplify privilege and credentialing processes

2. Home Care As Secure Employment

- Payment flexibility
- Competitive rate increase
- Pay non-licensed family caregivers

3. Home Care As Measured Care

- Federal: financial and logistical support to develop pediatric HCBS metrics
- State: monitor home care and build quality/access boards

Resources and Readings

Resources

- Illinois Title V Program: [Department for Specialized Care for Children](#)
- [Foster Health Lab](#)

Readings

- [Home Health Care for Children with Medical Complexity: Workforce Gaps, Policy, And Future Directions](#)
- [PediHome: Development of a Family-Reported Measure of Pediatric Home Healthcare Quality](#)
- [Employing Family Caregivers: An Innovative Health Care Model](#)
- [Children with Special Health Care Needs and Forgone Family Employment](#)