



The Next Steps to Improving Home Health Care for Children with Medical Complexity

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Today's Moderator

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Home Health Care For Children With Medical Complexity: Workforce Gaps, Policy, And Future Directions

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ORGANIZATION OF CARE

By Carolyn C. Foster, Rishi K. Agrawal, and Matthew M. Davis

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ABSTRACT With the medical and surgical advances of recent decades, a growing proportion of children rely on home-based care for daily health monitoring and care tasks. However, a dearth of available home health care providers with pediatric training to serve children and youth with medical complexity markedly limits the current capacity of home health care to meet the needs of patients and their families. In this article we analyze the workforce gaps, payment models, and policy challenges unique to home health care for children and youth with medical complexity, including legal challenges brought by families because of home nursing shortages. We propose a portfolio of solutions to address the current failures, including payment reform, improved coordination of services and pediatric home health training through partnerships with child-focused health systems, telehealth-enabled opportunities to bridge current workforce gaps, and the better alignment of pediatric care with the needs of adult-focused long-term services and supports.

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Home health care for children and adolescents is an understaffed health care model that does not meet the current needs of patients and families. Increasingly, pediatric patients are surviving conditions that were untreatable decades ago. While applaudable, hospital-based medical advances that have saved children from previously fatal conditions have not been matched with adequate home and community-based medical care, which leaves many parents to manage complicated medical care for their children at home alone, struggling to stay employed and healthy themselves. The primary challenge of the pediatric home health care crisis is to develop a trained and adequately compensated workforce to meet the needs of children and their families. In this article we analyze the policy context for this workforce gap. We also propose opportunities to address the current failures in providing a home health workforce for children and youth.

The origins of home health care for this special population are unique. In the early 1980s a child named Katie Beckett required a breathing machine to live, but she was institutionalized in a hospital because nursing care that would allow her to live at home with her family was financially inaccessible. Bipartisan legislation in the wake of her case, as well as the subsequent passage of the Americans with Disabilities Act of 1990, as interpreted by the US Supreme Court in its 1999 decision in *Olmstead v. L.C.*,¹ expanded access to Medicaid home and community-based services waivers that provided long-term services and supports for a broad array of children and adults with disabilities and a consequent reduction in institutional care.²

With medical advances that increase the likelihood of surviving a childhood disease, the medical needs of children with medical complexity are extending well into adulthood.³ Parents report increased need to forgo employment to care for their children with medical needs.^{4,5} Medicaid

Meet Today's Speakers



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Ask Questions!

We look forward to a lively discussion with our audience.
Enter questions in the GoToWebinar question box.



“Sarah’s” Story

A 15 month old diagnosed with an unexpected genetic disorder, Sarah needs a portable breathing machine and monitoring to live at home safely

- Parents were both working with employer-based insurance, but it does not cover home care nursing
- Sarah is eligible for Medicaid waiver, but even with it the parents cannot reliably identify qualified home nurses to care for her
- Sarah’s mother had to drop out of work-force and the family moved homes to accommodate

When faced with patient stories like Sarah's:

Conduct research to understand how home health care is serving children by examining:

- Current evidence base
- Measurement of current access and quality
- Identify key driving policy concerns

Current State of Home Health Care for Children

Summary of Home Health Care For Children With Medical Complexity: Workforce Gaps, Policy, And Future Directions

- 1. Growing population with diverse set of conditions**
 - Uniquely reliant on adult caregivers for health care tasks
- 2. Legally entitled services**
 - Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Medicaid Provision
- 3. Inadequate home health care workforce pool to care for them**
 - Non-competitive wages for highly skilled work
 - Few training opportunities
- 4. Current lack of evidence and quality measures incentivizes states to institute high-thresholds for service eligibility**
- 5. Leads to preventable hospital spending, hard on families and patients**

Policy Recommendations to Address Gaps and Areas of Improvement

Summary of Home Health Care For Children With Medical Complexity: Workforce Gaps, Policy, And Future Directions

1. Enhance access and readjust spending via payment reform

- Introduce increase in wages better matched to clinical needs, comparable to other skilled nursing labor

2. Improve quality through partnerships with child-focused care systems (e.g. trainings, telemedicine)

- Trainings: Children's hospitals are a source of clinical and technical expertise
- Real-time extension, telemedicine to support families and home nursing staff

3. Align with adult care to improve evidence base and inform quality measurement

- National data collection efforts
- Support quality measures to hold care accountable and track quality efforts

Cara Coleman, JD, MPH

Consultant, Family Voices and Instructor of Pediatrics, Virginia Commonwealth University Medical School



Key Thoughts

- Gaps, policy and future directions spot on for families
- Measure it for kids!
 - Can't (and actually do not) have quality care (incl. accountable, accessible, continuous, helpful) without measures
- Integration of home health within child-focused health care systems
 - Utilize family workforce expertise-as providers, coordinators, teachers, quality improvement specialists, advocates, etc.

One thing to change about the discussion

- Families and family-led organizations **MUST** be partners in care **AND** systems change
 - We are the engine- don't try to drive future directions without us!

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Key Thoughts

- Caregiver support
- Education & training of home health care professionals
- Single points of entry for services

Roy Maynard, MD

Medical Director, Pediatric Home Service and American Academy of Pediatrics Representative



Key Thoughts

- Factors that affect access to home health care
- Access to home health contributes to healthcare disparities
- Reimbursement and home health care
- Recommendations to expand access to home health care

Submit your questions



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Additional Resources

**HEALTH AFFAIRS BLOG—Workforce in the Community
Not Just Along For The Ride: Families Are
The Engine That Drives Pediatric Home
Health Care** Cara L. Coleman (April 18, 2019)

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