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

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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.^{4–6} Medicaid

spending for children with medical complexity disproportionately goes to hospital care (47 percent) instead of home health care (2 percent).⁷ This continues to raise the possibility that a more effective system of home health care could reduce hospital use for this population.^{7,8}

Policy Governing Home Health Care For Children

Although federal law has established a base of expected long-term services and supports, a complex state-by-state patchwork of policy governs the provision of home health care services to American children.² The *Olmstead* decision¹ provides an “integration mandate” for states to develop policies that promote the inclusion of people with disabilities so that they can live at home and in the community, rather than in institutions such as acute care hospitals. Children with Medicaid also are entitled to home health care services—including private duty nursing (“home nursing”)—through the Early and Periodic Screening, Diagnostic, and Treatment provisions of the Medicaid statute of 1967. Consequently, long-term services and supports are infrequently covered by private health insurance, given that there are pathways for families with higher incomes to gain Medicaid coverage for them through home and community-based services waivers, Section 1115 waivers, and other state-specific Medicaid mechanisms.⁹

Despite the goal of expanding options for long-term services and supports through these laws, substantial problems persist in accessing home-based care for children and youth. States vary widely in their use of waivers, which generally offer standard Federal Medical Assistance Percentage rates as compared with the enhanced federal match present in other state programs such as the Children’s Health Insurance Program.¹⁰ Reimbursement rates to states have been flat despite inflation, which translates to flat payment rates to home health agencies and their workforce. At least fourteen states have instituted pediatric waiting lists for Section 1915(c) home and community-based services waivers, which leads to eligible patients not receiving services.¹¹

While children and youth with medical complexity have been traditionally excluded from Medicaid managed care, a recent National Academy for State Health Policy fifty-state long-term services and supports review noted that one-quarter of states now provide them to children through Medicaid managed care programs.¹² According to the report, eleven of the fourteen states that provide managed care long-term services and supports use a risk-based system, most

commonly enrolling children into a comprehensive single managed care program that includes behavioral and physical health services. The remaining three states have stand-alone programs that focus only on long-term services and supports and behavioral health. While most shifts to managed care within Medicaid for children and youth with medical complexity have not been studied formally, there is some evidence that managed care may decrease health care expenditures for this group.¹³

Pediatric Home Health Care Workforce Challenges

Consequently, there is substantial variation across states in the extent to which children are in home and community-based versus long-term care settings (that is, nursing facilities).¹⁴ For patients able to access home nursing, the number of hours granted for a given patient may range from 20–30 hours a week to total coverage (24/7). Even when hours are approved for Medicaid payment, families often have difficulty finding home nurses, which leads to either prolonged hospitalizations or exhausted family caregivers.^{15,16}

Thus, the current home health care “system” for children depends substantially on cost shifting to families, with vital but informal labor provided by family caregivers—typically mothers.^{4–6} Parents of chronically ill children are less likely to work more than twenty hours per week and more likely to participate in casual than in regular employment compared to parents with otherwise healthy children.⁶ A national survey of family caregivers of children with a rare disease reported that 52 percent of family members had to go to part-time work or cut hours, 42 percent took a leave of absence, 31 percent turned down a promotion, 23 percent lost a job benefit, and 21 percent gave up working or retired early to meet the care needs of their children.⁵

Children with severe chronic lung conditions exemplify the challenges of workforce training for the pediatric home health care workforce. A study in Pennsylvania noted that families reported inadequate workforce nursing skills in respiratory assessment, airway care, and emergency preparedness.¹⁷ Unlike adults, who may be able to provide some level of self-care alone or with a personal care assistant, children typically must have medication and respiratory care administered for them, which requires clinical training and higher pay. Such children typically receive liquid medications through a tube in their stomach and require minute-to-minute lung monitoring. Nurses with intensive care experience are often most comfortable caring for

Home health care for children and youth with medical complexity illustrates the problem of an underfunded mandate.

such patients, but they receive substantially lower wages for home-based care. While new nursing school graduates sometimes work home health care shifts to broaden their skill set, nursing schools typically do not prepare graduates to care alone for technology-dependent children.

Moreover, no uniformity exists in how home health care agencies document and receive the orders necessary to maintain their services.¹⁸ Documentation is often still paper based, with agencies using different templates—including for key information such as medication reconciliation.¹⁸ Even when agencies use electronic health records, electronic ordering is often not available, which can lead to discrepant and out-of-date paper orders and can frustrate ordering physicians, home nurses, and families alike.¹⁸

Collectively, such fragmentation—coverage mandates varying by state, the need for and unavailability of a specialized workforce, and multiple and onerous documentation requirements—leaves home health care isolated from typical health care delivery streams for children and youth. The need for specialized, highly skilled, and integrated home health labor to care for these medically complex children also collides with a national shortage of home health care providers.^{19,20} State scope-of-practice laws differ regarding who may provide what level of home health care. Where only registered nurses are eligible, workforce options are especially limited.

Pediatric Home Health Care Workforce Payment

Home health care for children and youth with medical complexity illustrates the problem of an underfunded mandate. In the current era of constrained state budgets, there is no evidence base to guide eligibility criteria for state-based waivers and thus no guidance to determine the need for long-term services and supports. States

therefore have a fiscal incentive to keep thresholds sufficiently high to control utilization. Fee-for-service payment structures that emphasize procedural and higher-acuity care have discouraged investment in long-term services and supports for decades, which has exacerbated this problem.²¹

Consequently, low Medicaid payments de facto support a workforce of low-wage home health workers. Median hourly wages for home health care services in 2017 were \$33.77, compared to an average of \$36.45 for inpatient care nationally. Of note, these figures mostly rely on Medicare payment and do not take into account locally prevailing wages.²² For example, through conversations with home health care agencies, we have found that pediatric home health agencies in the Chicago area can offer only about \$26 per hour for a private-duty nurse to provide home care to a Medicaid beneficiary, regardless of experience, compared to about \$36 per hour that an entry-level nurse could earn at a hospital. Pay for home nursing care in less urban areas may be as low as about \$19–\$21 per hour, compared with roughly \$23–\$38 per hour for hospital nursing care. Notably, in Illinois, the education system pays nurses for the hours that a patient is in school at a higher rate (about \$55 per hour), which motivates home health providers to prefer patients who can attend school.

As a result, there are few incentives for home health workers with the requisite training and experience to serve in the pediatric home setting instead of taking higher-paying hospital-based jobs.²⁰ Compassion fatigue, burnout, and the difficulties of navigating professional boundaries in the home are additional challenges reported by pediatric home nurses.^{23,24} To sustain their business model, home health agencies that specialize in children often need to balance private-pay and Medicaid patients in an effort to recruit and retain high-quality workers, which leads to perceived inequitable access for socioeconomically disadvantaged families.

Family advocates have used various legal challenges to compel states to provide long-term services and supports for their children.^{25–29} A class-action lawsuit in Washington State brought by the Northwest Justice Project against the state health care authority that was decided in 2016 identified low wages as a key contributor to the lack of home nursing for eligible children and specified necessary increases in such wages.²⁹ Additional suits in Illinois, Texas, Georgia, and Florida highlight how families are resorting to litigation to address inadequate access.^{25–29}

Ramifications of the lack of skilled home health workers for children ripple throughout the health care system, as children's hospitals

struggle to discharge children with medical complexity. In some locations, scarce and costly pediatric intensive care beds are being used for de facto long-term care because of a lack of home nursing coverage and pediatric postacute care options.^{15,19} In a recent prospective multicenter study in Minnesota of 185 children who required home nursing, 57 percent of hospital discharge delays were directly attributable to lack of home health care, accounting for 1,454 hospital days.¹⁵ Hospital costs resulting from these delays totaled \$5.72 million, compared to the estimated \$769,326 that it would have cost to care for the children at home. In an analysis at our institution, we also found that hospital discharge delays due to the private duty nursing shortage lead to months of unnecessary hospital days and millions of dollars in avoidable hospital charges in the aggregate.³⁰ Home health agencies, in turn, lose revenue when patients are hospitalized and sometimes drop patients as clients when a hospitalization is prolonged. Staff nurses are then reallocated to other clients so that the agencies can remain financially viable.

Transitional and long-term care facilities may offer opportunities for training and transitional support for families before patients are discharged home. States differ, however, in allowing these services. One example of a facility is Almost Home Kids, an Illinois pediatric community-based health care center that provides a supportive, educational alternative to the hospital for children with medical complexity and their families before the children go home and when the families need respite.³¹ States vary, however, in their definitions, licensure, and regulations of such facilities, which affects the available out-of-home options for children and youth nationally.³²

Recommendations For Policy And Program Changes

While the challenges to providing high-quality home health care are multifaceted, policy and program approaches can alleviate workforce gaps and expand access to home health care for children and benefit families, payers, and providers. Accessible, high-quality home health care has the potential to improve health outcomes in a patient- and family-centered fashion and reduce the use of emergency and hospital care. A combination of payment reform, improved pediatric home health training opportunities through partnerships with child-focused health systems, telehealth-enabled opportunities to bridge current workforce gaps, and the consideration of dynamics in home health care for adults can address fundamental vulnerabil-

ities in the current system.

PAYMENT REFORM State payment for pediatric home-based care should be competitive with that for other forms of skilled nursing care. Payment increases—perhaps tapping fiscal sources that are tied to higher Federal Medical Assistance Percentage rates, depending on state circumstances—could include the stratification of rates for higher-complexity cases and, in areas of shortage, to provide incentives for nurses to care for patients most at risk for prolonged hospitalizations. For example, care of patients who required continuous respiratory care would be reimbursed at a higher rate than care for patients who only need to be given medication every few hours. Paid caregiving for trained family members, which is not permitted in most states, could further expand the workforce while mitigating the financial impact on families. Since home health agencies usually deduct administrative fees from state payments before paying nursing staff, allowing families to contract directly with nurses instead of through agencies could offer a higher, more enticing wage to home nurses.

Calls for higher wages for Medicaid-reimbursed home care services can be expected to be met with skepticism from policy makers. However, given that children with medical complexity have intensive medical needs and frequent exacerbations of chronic health conditions, investment in higher-quality home health care would be a cheaper option than the repeated or prolonged hospitalizations that currently occur.^{7,33} Instead of viewing home health care as a drain on state budgets, the Minnesota multicenter study suggests that states should consider it as a tool to prevent hospitalizations and facilitate more timely discharge when hospitalizations occur.¹⁵ Furthermore, states could phase in increases in home health care payment over a period of time, moving toward a goal of hourly nursing wages in the home setting that approximate wages in the inpatient setting.

The potential role and impact of managed care on pediatric long-term services and supports are unknown. The National Academy for State Health Policy issue brief noted that only four states—Delaware, Tennessee, Virginia, and Texas—specify network adequacy standards for pediatric long-term services and supports.¹² To achieve managed care goals, states should carefully review network adequacy and consider competitive payment for home nursing in their managed care contracts to shift care from expensive hospital settings to less costly care delivery settings, such as the home. Evaluations of network adequacy must consider more than single-year savings and direct costs to states. Instead, they should include longer-term effects such as

An improved evidence base is needed for what constitutes accessible high-quality pediatric long-term services and supports.

lost family wages (that is, taxable income) from family caregivers who were forced to leave their own employment to fill workforce gaps.

INTEGRATION OF HOME HEALTH WITHIN CHILD-FOCUSED HEALTH CARE SYSTEMS With the advent of accountable care organizations and value-based payment arrangements between payers and health care systems, creating systems that align inpatient, ambulatory, and community services has gained appeal. Hospitals—including children's hospitals—are increasingly penalized for readmissions, the origins of which may be based in the home, where hospitals traditionally have little influence.

We propose more formal collaborations between child-focused hospitals, academic institutions, home health agencies, and nursing education programs to create a robust pool of nurses in pediatric home health care and manage patient care. Pediatric hospitals can help shape how to train nurses and clinical nursing assistants to have the right skill levels matched to levels of patient need, step in to modify the level of nursing care when gaps occur, supplement home health agency oversight with supervisory support, and work with patients' primary care physicians and primary care medical homes to coordinate home-based care between emergency department and hospital visits. Among successful examples of targeted nursing education are the Trach Safe Emergency Airway Management Course at Seattle Children's Hospital and Nitty Gritty Nursing: Improve Your Community Nursing Skills for Children Who Are Medically Fragile and Technology Dependent at our institution. Alternatively, the University of Massachusetts Medical School's Community Case Management program keeps children and adults out of institutional care through coordinating care and helping families navigate the administrative hurdles involved in long-term services and supports coverage. Through such partnerships and programs, child-focused health institutions can ful-

fill their own patient care goals and attend to fiscal constraints without fully incorporating the home health business model, if desired. Home health agencies would similarly benefit from a better-trained workforce and greater coordination with child-focused health systems in their service areas.

Another needed advancement is the development of uniform order forms and documentation for home health care, including electronic ordering, to facilitate timely and accurate orders for home care providers (that is, there is a need for interoperative health care records). Ideally, such a system would enable home nurses to review the orders for correctness in a timely manner to enact necessary changes to care at home to minimize error and expedite care, especially after a hospital discharge.

As the value-based payment system expands, pediatric hospitals that do not already offer home care programs may wish to do so, by capitalizing on their already highly trained workforce as a way to better monitor the care that is being provided at home.

ADVANCING COMPLEX HOME-BASED CARE THROUGH TELEHEALTH Incorporation of telehealth in the home health care of children with medical complexity also can link institution-based specialists with home nurses to monitor patient status, manage symptoms, and adjust care in real time. Videoconferencing and remote home monitoring of clinical parameters such as respiratory physiology and blood sugar offer tools to link children's families, health care providers, and home health care staff.³⁴ These examples of telehealth tools are increasingly vital, especially for children and youth with medical complexity who live in remote or otherwise underserved areas or who are difficult to transport. They can sustain success in home-based care and avert hospitalizations.

Telehealth may also provide a bridge to address workforce shortages, by supporting nurses without pediatric experience—and potentially even nonclinical aides or extended family caregivers—to care safely for more patients at home through videoconferencing with pediatric specialists and home health agency nursing supervisors.^{35,36} One successful model has already demonstrated a decrease in clinic and emergency department visits through direct support of family caregivers for children with home breathing machines.³⁵ Importantly, as telehealth increasingly includes remote patient monitoring, the home health care workforce will require appropriate training and education to leverage the maximum benefit of these clinical tools, which have been shown to be feasible and highly rated by families.

ALIGNMENT WITH HOME-BASED CARE FOR ADULTS Children with medical complexity and technology dependence are living longer as a result of technological advances, so their numbers and the demand for a home health care workforce are increasing.² In addition, as adults live longer, they also will require more home-based care. Combined, these two trends will have a substantial economic impact on family caregivers and the demand for paid caregiving. In 2015 an estimated 43.5 million US adults had provided unpaid, health-related care to an adult or child in the prior twelve months, providing an average of 24.4 hours of care per week.³⁷ It will be essential to align pediatric care with adult care by including pediatric health care professionals in federal and state long-term services and supports policy working groups and on home health care agency boards.

Better alignment with adult care to address the need for more pediatric home health care services must also be linked to the need for quality measures for such care. While some metrics exist to evaluate home health care delivery for adults, there are no equivalent measures for pediatric home health care. The Centers for Medicare and Medicaid Services' Home Health Compare has no pediatric-specific items,³⁸ and national surveys on home health care typically do not include children.³⁹ Therefore, state managed care contracts for long-term services and supports lack pediatric-specific measures to evaluate the quality of care provided.¹² It will be essential for pediatricians to be involved in the development or adaptation of government-based, home health care–focused quality measures in the near future and in the creation and implementation of Medicaid network standards. Consideration of children in national metrics is necessary to ensure that pediatric home health care services are of good quality and commensurate to their cost.

An improved evidence base is needed for what constitutes accessible high-quality pediatric long-term services and supports. Future sur-

veys and data reporting requirements in this area should include patients younger than age eighteen to enhance our understanding of pediatric utilization nationally and by state, to understand how state-based waiver eligibility affects utilization. Future research should include rigorous evaluation of the current state of home nursing quality, including the development of pediatric-specific measures that take into account the family context, to support future interventions designed to improve access and training.

Conclusion

Home health care for children and youth with medical complexity in the United States is a patchwork of policies and programs that does not currently meet the medical needs of many patients; unnecessarily prolongs hospitalizations; and relies on an insufficient, inadequately trained workforce. Although there are no formal metrics of quality for pediatric home health, it is evident from several national surveys that family caregivers are frequently shouldering enormous burdens that lead them away from their own gainful employment and create social, emotional, and financial hardship.

There are, however, immediate opportunities to address some of these workforce issues through more competitive payment, better training, and better coordination of services among child-focused hospitals and health systems and home health nursing services. In addition, wider use of telehealth can create efficiencies. Finally, with an improved evidence base, there would be opportunities to better align pediatric and adult home health care services—particularly in terms of network adequacy and quality measurement. While supportive public policies exist, additional policy-based solutions will be required to ensure that adequate, affordable, and measurably high-quality home health care services are available to children and adults. ■

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