



# Financing of Pediatric Home Health Care

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Pediatric home health care is an effective and holistic venue of treatment of children with medical complexity or developmental disabilities who otherwise may experience frequent and/or prolonged hospitalizations or who may enter chronic institutional care. Demand for pediatric home health care is increasing while the provider base is eroding, primarily because of inadequate payment or restrictions on benefits. As a result, home care responsibilities assumed by family caregivers have increased and imposed financial, physical, and psychological burdens on the family. The Patient Protection and Affordable Care Act set forth 10 mandated essential health benefits. Home care should be considered as an integral component of the habilitative and rehabilitative services and devices benefit, even though it is not explicitly recognized as a specific category of service. Pediatric-specific home health care services should be defined clearly as components of pediatric services, the 10th essential benefit, and recognized by all payers. Payments for home health care services should be sufficient to maintain an adequate provider work force with the pediatric-specific expertise and skills to care for children with medical complexity or developmental disability. Furthermore, coordination of care among various providers and the necessary direct patient care from which these care coordination plans are developed should be required and enabled by adequate payment. The American Academy of Pediatrics advocates for high-quality care by calling for development of pediatric-specific home health regulations and the licensure and certification of pediatric home health providers.

## INTRODUCTION

The home of the pediatric patient can be an appropriate, and is often the preferred, site for the provision of health care services to address a wide range of serious and complex medical needs or developmental disabilities. Indeed, many pediatricians believe that the patient's home provides a healing environment and offers psychological benefit for the child and family. In the United States, almost 500 000 children and

## abstract

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youth with special health care needs require a range of medical and therapeutic services in their home.<sup>1</sup> Although cross-sectional data on the demographic characteristics and needs of this population are limited, what is known is that children receiving home health care are more likely to have serious or complex medical conditions and functional limitations and be insured by a Medicaid plan, by a Children's Health Insurance Program (CHIP) plan, or by both a private insurance and a Medicaid/CHIP plan.

Over the past several decades, a number of factors have affected the scope of pediatric home health care services, including the following: higher rates of survival of extremely preterm infants; more children with serious or life-limiting complex medical conditions, including those recovering from physical trauma; the miniaturization and simplification of life-sustaining medical equipment; the deinstitutionalization of children with severe medical and mental health needs; family preferences for care in the home instead of in the hospital; and cost-containment pressures to prevent or shorten hospital stays. Home care for children involves a broad array of professional and paraprofessional services, including the following: nurses; physical, occupational, and speech-language therapists; respiratory therapists; medical social workers; psychologists; dietitians; and home health or personal care aides. Private duty (also known as extended-hours) nursing is necessary for a subset of children with complex and frequently technology-dependent conditions. A recent study of the utilization of postacute services in children found that almost one-half of pediatric patients discharged from the hospital from acute care hospital settings are neonates.<sup>2</sup> This study also noted that home health services seem to be infrequently and variably used in children compared with adults,

even when assessing use in children with multiple chronic conditions and technology assistance. In addition, significant state-to-state utilization disparities exist across the United States.

Family members assume significant responsibility and are often the primary providers of home health services to children. Family members often facilitate needed communication between service providers, case managers, and payer sources. Many family members who care for their children at home report significant physical, emotional, social, and financial burdens.<sup>3</sup> The National Survey of Children with Special Health Care Needs found that a significant percentage of families provide greater than 21 hours per week of health care at home and spend upward of 11 hours per week on care coordination.<sup>1</sup> This survey also reported that 25% of families curtail work or leave their jobs to care for their children. These consequences can significantly impair family functioning and quality of life. A recent study found that parents self-reported poorer physical health and cognitive function when their medically complex, technology-dependent children received care in the home compared with medical day care or long-term care facility settings.<sup>4</sup> Maintaining all care in the home setting required tremendous emotional, financial, and time investment by the parents that compromised their social lives and employment.

Since 1989, federal regulations have specified that children aged younger than 21 years who are enrolled in Medicaid are entitled to Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefits, which the American Academy of Pediatrics (AAP) believes are the standard for comprehensive essential medical services for these children. Home health services, including private duty nursing services, personal

care services, primary care case coordination, and hospice care, are federally mandated Medicaid EPSDT benefits "when necessary to correct or ameliorate a mental or physical illness or condition."<sup>5-7</sup> National health expenditure data reveal that pediatric home health costs rose steadily from 2002-2010 and totaled \$6.7 billion in 2010. This total represented 9% of all home health expenditures and 2% of all children's health expenditures. The vast majority of these expenditures (\$6.2 billion) were funded by Medicaid.<sup>8</sup> Among children with more complex medical conditions, home care costs can exceed 10% of health care expenditures. For example, in the Florida Ped-I-Care program (a Medicaid provider-sponsored network for children and youth with special health care needs), home health care expenses for 2012-2014 averaged \$190.60 per member per month, or 22.7% of the total expenditure for children receiving Title XIX benefits. For children insured by Medicaid in Clinical Risk Groups 5b through 9 in outpatient centers participating in a Children's Hospital Association project funded by the Centers for Medicare & Medicaid Innovation, an analysis by Truven Health Analytics demonstrated that home health care expenditures averaged 26% of the total cost (data used with approval).

The AAP advocates for home health care as a patient- and family-centered delivery system that can be integrated within a comprehensive care program and linked to the full resources of the medical home, medical and surgical specialties, rehabilitative and habilitative therapies, hospice and respite care, care coordination, other related community-based supports, and hospitals. Each child can benefit from a readily accessible and comprehensive written plan of care that represents a consensus among the family, the patient, and

the caregivers. The ability of the medical home and other specialty providers to interact with the child, family, and home health providers using telehealth technologies has the potential to optimize care, to minimize family disruption, and to avoid unnecessary medical utilization. Children who require home care represent the very population for whom the potential for benefit and cost savings is highest through prevention of excessive emergency department and inpatient hospital utilization.

## PROBLEM STATEMENT

The Medicaid program permits each state to define the medical necessity for evaluation and treatment and allows latitude in establishing the duration and/or scope of a medically necessary treatment or benefit. In practice, state Medicaid agencies differ with respect to decisions regarding eligibility for benefits, duration and scope of benefits, the amount of payment, the required provider expertise for service provision, and provider documentation requirements. These differences lead to inconsistent provision of home care services across states.<sup>2</sup> The increasing outsourcing of care to Medicaid managed care organizations has exacerbated problems with home health care services because of a number of factors that include dilution of pediatric expertise, limited provider networks, burdensome procedures for prior authorization, and potential payments at less than state Medicaid rates. Eligibility criteria for EPSDT services are not uniformly interpreted, particularly when essential treatments required by a child (eg, home care, hospice care) differ from or exceed those routinely covered for adults by private insurers and Medicare. Appeals to reverse state-level Medicaid denials for home care

services often require a considerable time investment by a family and the child's physician, without any federally based oversight or ombudsman-like support mechanism.

Access to pediatric home care services also is affected by financial factors that affect the availability of qualified pediatric home health care providers. Among the most significant is the lack of private health insurance benefits for extended home health services, including nursing, rehabilitation/habilitation, durable medical equipment (DME), and respite care. Medicaid payments may be less than the actual total cost of the prescribed service, discouraging providers from caring for these children in the home setting. In particular, low Medicaid payments for skilled private duty nursing can impede the ability of home health agencies to offer staffing with sufficient skilled nurses to care for medically complex children. As a result, children will remain in the hospital or be placed in inpatient or residential facilities. In some states, thousands of children are on waiting lists for home health services. Many private insurers and CHIP plans have limited home health benefits for children, critically affecting those children with medical complexity who require longer term services. Coverage for DME often is inadequate, especially when it is bundled into payment for visits or into prospective payment arrangements. Such systems of bundled payments create disincentive or delays in obtaining coverage for DME.

Both private and public insurance offer limited or no physician payment for pediatric care coordination, home care management, or telehealth, although these are recognized key components to quality care delivery for children with complex medical needs. Lack of payment for these services limits access to medical home practices and qualified

pediatric home health providers. Additional costs incurred to comply with and document adherence to regulatory requirements represent an unfunded mandate that exacerbates home care providers' financial burdens. The reduction and elimination of pediatric capacity in many home health agencies and hospital-run home health programs are widespread and have led to decreased access to quality home care services in many communities.

Family members are often the primary providers of home care to children, and many are forced to choose between continuing employment and caring for their child at home. Partnership with professionals is essential, as is information, education, training, resources, and support so that families can provide the skilled care their children need. However, the resources to train and support family caregivers are limited. Although there are opportunities for Consumer Directed Personal Assistance Programs, many states do not participate in these plans, and funding for a parent (as opposed to a relative or a stranger) through these programs is not available. Parents can likely be the best caregivers, but without such support, many parents must maintain employment and delegate care of their children to other in-home providers or to residential facilities.<sup>9</sup>

Because policies that regulate the delivery and financing of health care are developed most often with the needs of aging adults in mind, existing standards have become increasingly irrelevant to pediatric home health care, given the disparate needs of children with medical complexity or developmental disabilities. In many states, agencies are not required to provide pediatric-specific training or to develop pediatric-specific competencies. Because of the lack of pediatric-specific home health regulations

and payment structure, children requiring home health services may not receive the necessary expert care at home. They may experience life-threatening disease and other medical complications, risk of serious injury, more frequent readmission to hospitals with attendant accrual of higher health care costs, and excessive family burden. Children remain hospitalized or are placed in residential facilities at a much higher cost because pediatric home health care services are inadequate to allow home discharge.<sup>9</sup> Certain medical complications are more likely when children are in the hospital or long-term inpatient facilities rather than in an appropriately supervised home care setting.<sup>10</sup>

States and payers are, at times, working together to build new models of care designed to contain cost and improve quality. However, most of these delivery reforms and the standards associated with them concentrate on adults with chronic conditions and not on children.<sup>11</sup>

## CONCLUSIONS

Pediatric home care involves the delivery of medical care in the home to children with serious and often complex medical conditions or with developmental disabilities. Some of these children depend on technological assistance for survival. The number of children who can benefit from home health services is steadily increasing as medical providers and parents express concerns about significant gaps in existing services. To advocate for continued improvements in pediatric home care, the AAP has developed the following set of recommendations pertaining to regulatory oversight, care delivery systems and payment, and further research. Implementation of these recommendations is critical so that children and families will have enhanced access to high-quality medically necessary services and all

the benefits that essential pediatric home care provides.

## RECOMMENDATIONS

### Regulatory

1. The Centers for Medicare & Medicaid Services (CMS) should explicitly recognize the full breadth of pediatric home health care services as elements of pediatric services, the 10th category of essential benefits listed in the Patient Protection and Affordable Care Act (Pub L No. 111-148 [2010]).
2. All public and private payers should incorporate pediatric home health care services into their essential health benefits.
3. The US Department of Health and Human Services should provide regulatory guidance to the states establishing their essential health benefit standards to ensure inclusion of the full range of pediatric home health care services, clearer specific guidance on medical necessity in children, and flexibility in prescribing the duration and frequency of services in consideration of the evolving status of the individual child. The US Department of Health and Human Services should also take steps to ensure that home health care networks attract a provider base that is sufficient in number and skill sets to meet the needs of children. The EPSDT criteria for essential services for children should be endorsed as the standard definition.
4. CMS should appoint a federal ombudsman program to compile and evaluate provider and patient complaints regarding access to care in the Medicaid program. This program would monitor state-level denials for EPSDT-mandated home health care services, DME, and assistive technology to identify and redress patterns of unwarranted denials for necessary care.
5. Federal and state health agencies should develop home health care regulations that address the unique needs of children. In this process, family knowledge and experience related to the need for and the impact of home care on the family should be integrated into the regulatory processes that seek to develop policies or to establish other program or resource requirements.
6. Pediatric home care should be delivered consistent with a written plan of care developed by the child's medical care providers in consultation with the child's family and, as appropriate, the child. Physicians, home health agencies, third-party payers, and managed care plans can use the recommendations published by the AAP in *Guidelines for Pediatric Home Health Care*<sup>12</sup> for the purpose of determining the frequency and duration of home health services. Physicians have a special responsibility to prescribe the types, quantity, and intensity of home health services that are appropriate for the needs of the individual child and family. Physicians should modify their prescriptions when there is a change in the child's needs or when the goal of therapeutic services has transitioned from habilitation or rehabilitation to maintenance of function. Home health agencies should communicate such changes to the prescribing physician in a timely manner.
7. Personnel responsible for direct care should be properly credentialed, licensed, or certified.

### Care Delivery and Payment

1. Medical necessity for pediatric home health care should be more clearly defined to include services that assist in achieving,

maintaining, or restoring health and functional capacity and that are appropriate for the age and developmental status and take into account the needs of the individual child. Because few scientific studies have examined the effectiveness of home health care for specific pediatric conditions, medical necessity standards should be based on professional standards of care for children or on a consensus of best pediatric practice. Coverage of home health care should not be denied in the absence of conclusive scientific evidence.<sup>13</sup>

2. Payment for services should be adequate to support the appropriate depth and expertise needed to ensure the provision of high-quality pediatric home health care. To accomplish this goal, payments should be at levels that permit home health agencies to attract and retain appropriately credentialed and skilled clinicians and ancillary personnel for pediatric intermittent care and shift/private duty care as well as to cover the indirect costs of clinical management and support of in-home staff. Payment adjustments should also take into account the costs associated with preparation and continuing education of nurses in pediatric competencies, intensive care, and technological skills.
3. Public and private payers should pay physicians for care coordination, case management, and telehealth encounters to ensure comprehensive and continuous care for children within the medical home.<sup>14</sup> Payers should recognize that many children with medically complex conditions benefit from concurrent standard medical and hospice care.
4. Expansion of current consumer-directed personal assistance programs is warranted, and all states should be encouraged

to participate. Such expansion should include the development of care and payment standards for all family caregivers, including parents, who assume significant home nursing or personal care responsibilities for their children. Appropriate preparation, training, and support for family caregivers should be available.

5. To lessen disincentives or barriers to coverage of medically necessary DME in the course of planning transitions to home care, payment for DME should not be bundled into payment for visits or into prospective payment arrangements for intermittent care and should include first-dollar coverage for appropriate and necessary DME.

#### Research and Demonstrations

1. CMS should analyze Medicaid pediatric home health care payment rates across all states to ensure that eligible children have access to medically necessary services nationwide.
2. CMS should analyze the net actuarial impact of adequate funding of pediatric home health care services and project the effect on state Medicaid funding.
3. CMS should analyze opportunities to expand eligibility for long-term care coverage for children under the new Community Living Assistance Services and Supports Act (Title VIII of the Patient Protection and Affordable Care Act), which was established as part of health care reform.
4. Among populations of children for whom telehealth technologies become integrated into medical home care protocols as a consequence of payment reform, payers should fund prospective studies that evaluate the effects of telehealth on health outcomes, patient and family experience of care, and total health care expenditures.

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#### ABBREVIATIONS

AAP: American Academy of Pediatrics  
CHIP: Children's Health Insurance Program  
CMS: Centers for Medicare & Medicaid Services  
DME: durable medical equipment  
EPSDT: Early and Periodic Screening, Diagnosis, and Treatment

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