



# Financing of Pediatric Home Health Care\*

Committee on Child Health Financing, Section on Home Care

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of All Children

## ABSTRACT

In certain situations, home health care has been shown to be a cost-effective alternative to inpatient hospital care. National health expenditures reveal that pediatric home health costs totaled \$5.3 billion in 2000. Medicaid is the major payer for pediatric home health care (77%), followed by other public sources (22%). Private health insurance and families each paid less than 1% of pediatric home health expenses. The most important factors affecting access to home health care are the inadequate supply of clinicians and ancillary personnel, shortages of home health nurses with pediatric expertise, inadequate payment, and restrictive insurance and managed care policies. Many children must stay in the NICU, PICU, and other pediatric wards and intermediate care areas at a much higher cost because of inadequate pediatric home health care services. The main financing problem pertaining to Medicaid is low payment to home health agencies at rates that are insufficient to provide beneficiaries access to home health services. Although home care services may be a covered benefit under private health plans, most do not cover private-duty nursing (83%), home health aides (45%), or home physical, occupational, or speech therapy (33%) and/or impose visit or monetary limits or caps. To advocate for improvements in financing of pediatric home health care, the American Academy of Pediatrics has developed several recommendations for public policy makers, federal and state Medicaid offices, private insurers, managed care plans, Title V officials, and home health care professionals. These recommendations will improve licensing, payment, coverage, and research related to pediatric home health services.

## INTRODUCTION

The home of the pediatric patient is an appropriate and often preferred site for the provision of health care services to address a wide range of conditions. According to national estimates,<sup>1</sup> more than 500 000 children use home health services in the United States.\* Children receiving home health care have a diverse array of diagnoses, severity levels, and complications. The 4 most common diagnoses are cerebral palsy, failure to thrive, developmental delay, and preterm birth, accounting for approximately 15% of the pediatric home health population. Although many children receiving home health care depend on technology, the vast majority do not.<sup>2</sup> Research also reveals that young children are more likely to receive home health care than are older children and adolescents.<sup>1</sup>

Over the past 20 to 30 years, the demand for pediatric in-home services has grown substantially as a result of several factors including the increased survival of preterm infants, trauma patients, and those treated in PICUs; medical and surgical

[www.pediatrics.org/cgi/doi/10.1542/peds.2006-1489](http://www.pediatrics.org/cgi/doi/10.1542/peds.2006-1489)

doi:10.1542/peds.2006-1489

All policy statements from the American Academy of Pediatrics automatically expire 5 years after publication unless reaffirmed, revised, or retired at or before that time.

\* The Medical Expenditure Panel Survey<sup>1</sup> reports that in 2000, 560 464 children 0 to 18 years of age had home health expenditures. National estimates were based on relatively small sample sizes. The National Survey of Children With Special Health Care Needs ([www.cdc.gov/nchs/about/major/slaits/cshcn.htm](http://www.cdc.gov/nchs/about/major/slaits/cshcn.htm)) reports that 505 459 children with special needs 0 to 18 years of age needed home health care in 2001.

### Key Words

pediatric home health care, financing  
pediatric home health, coverage, payment

### Abbreviations

AAP—American Academy of Pediatrics  
TEFRA—Tax Equity and Fiscal Responsibility Act  
SCHIP—State Children's Health Insurance Program

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275). Copyright © 2006 by the American Academy of Pediatrics

treatment advances; miniaturization and simplification of life-sustaining equipment; family preferences for home versus hospital care; and cost-containment pressures to limit or avoid hospital stays. Moreover, home health care has been shown to be a cost-effective alternative to inpatient hospital care.<sup>3-5</sup> Today, the range of services provided to children in the home has broadened to include not only rehabilitative care but also intravenous administration of antimicrobial agents and other medications, parenteral nutrition, nasogastric or enterostomy feedings, peritoneal dialysis, wound care, oxygen and mechanically assisted ventilation, chronic pain management, complex medical and surgical care, psychosocial support, respite, and hospice care. Registered nurses are the primary providers of pediatric home health care under the direct supervision of the physician.<sup>6</sup> Other health professionals providing in-home care to children are physical and occupational therapists, speech pathologists, medical social workers, nutritionists, licensed practical/vocational nurses, home health aides, and personal care aides.

National health expenditure data reveal that pediatric home health costs totaled \$5.3 billion in 2000. This represents one fifth of all home health expenditures but less than 1% of all children's health expenditures. On average, the per-child cost of home health care was \$9421 and ranged from a low of \$70 to a high of \$136 969. By far, Medicaid was the major payer of pediatric home health care (77%), followed by other public sources (22%). Private health insurance and families each paid less than 1% of pediatric home health expenditures.<sup>1</sup>

The American Academy of Pediatrics (AAP) recognizes the growing trend to provide health care services for children in their homes. The AAP has issued a policy statement for the provision of home health care services<sup>6</sup> and also a guide on the management of pediatric patients in the home.<sup>2</sup> To advocate for improvements in the financing of pediatric home health care, the AAP has developed this financing policy statement for its members, public policy makers, federal and state Medicaid officials, private insurers, managed care officials, Title V officials, and home health care professionals. It contains recommendations for improving public and private insurance coverage, payment, and authorization policies.

### GENERAL ACCESS PROBLEMS

Access to pediatric home health care services is inadequate throughout most of the United States. The most important factors affecting access to home health care are the inadequate supply of clinicians and ancillary personnel, shortages of home health nurses with pediatric expertise, inadequate payment, and restrictive insurance and managed care policies.<sup>7</sup> As a result, many home health agencies and hospital-run home health

programs have reduced or eliminated their pediatric home health capacity in the last few years.

Unfortunately, health care financing policies have not kept pace with the changing demand and complexity of pediatric home health care. As a result, children requiring home health services are at risk of receiving inadequate care at home and experiencing life-threatening disease and other medical complications; serious injury; more frequent readmission to hospitals; higher health care costs; and excessive family burden. Many children must stay in the NICU, PICU, or other pediatric wards and intermediate care areas at a much higher cost because of inadequate pediatric home health care services.

### MEDICAID LIMITATIONS

Because more than three fourths of all pediatric home health expenditures are paid for by Medicaid, understanding the limitations of Medicaid's home health care policies is critical. Unlike private health insurance, Medicaid provides a comprehensive home health benefit for children that includes part-time or intermittent nursing services, home health aide services, medical supplies and equipment, and, at states' option, physical, occupational, and speech therapy. Although states are able to limit the amount, duration, and scope of coverage of home health services for adults, these limits, because of requirements in the Early Periodic Screening, Diagnostic, and Treatment (EPSDT) service, cannot apply to children, provided the services are determined by the state to be medically necessary. In addition, states wanting to enhance their home health benefit package or increase eligibility to children from higher-income families can seek a home and community-based waiver. Fifty states are currently implementing such waivers. States also have the option of extending regular Medicaid eligibility to children who would have been eligible for Supplemental Security Income and Medicaid if they received their care in a nursing home or hospital under the "Katie Beckett" or Tax Equity and Fiscal Responsibility Act (TEFRA) eligibility option,<sup>8</sup> and 20 states have elected to use this option.

The main financing problem that pertains to Medicaid is low payment. Specifically, Medicaid agencies have been criticized for paying home health agencies at rates that are insufficient to provide beneficiaries with access to home health services. In many states, families complain that they are unable to secure nurses to fill all of the hours determined to be medically necessary. Correspondingly, home health agencies report difficulties recruiting and retaining qualified nurses because of low payment rates, payment delays, and restrictive policies regarding overtime. Not surprisingly, many home health agencies simply do not accept Medicaid referrals. Faced with these problems, families have attempted to hire their own independent nurses but have reportedly confronted significant payment obstacles. In addition, pedi-

atricians report that state Medicaid agencies and their contracted managed care organizations seldom allow them to bill for home visits, telephone care payment, or the time required for oversight and coordination of home health care plans despite the existence of codes for these services.

Other complaints about pediatric Medicaid concern restrictive interpretations of medical necessity and benefit definitions that follow adult home health care standards. Still other complaints include excessive paperwork and time required for authorization, retrospective denials, and increasingly long waits to gain eligibility for home, community-based, and TEFRA waivers, particularly in the last few years with state budget difficulties.

### **STATE CHILDREN'S HEALTH INSURANCE PROGRAM LIMITATIONS**

Among states operating non-Medicaid State Children's Health Insurance Program (SCHIP) plans, home health coverage is much more generous than private health insurance. Of the 36 states with non-Medicaid SCHIP plans, only 1 state does not cover home health services. Approximately one quarter of these states impose visit limits, and copayments or coinsurance are rarely charged.<sup>9</sup> Little has been written about SCHIP authorization and payment limits, but because most SCHIP plans rely on the same administrative infrastructure as Medicaid, more stringent limits seem inevitable.

### **PRIVATE HEALTH INSURANCE LIMITATIONS**

The extent of home health coverage under employer-sponsored health insurance plans is not well known. A 1998–1999 study of commonly sold health maintenance organization and preferred provider organization products in each state found that almost all plans covered home health services. However, 83% did not cover private-duty nursing, 45% did not cover home health aides, and more than one third did not cover home-based physical, occupational, or speech therapy. In this study, almost half of the plans imposed visit (typically 60 visits) or monetary limits, and the most often used cap was \$5000. Condition exclusions were also imposed in two thirds of plans, usually for impairments not caused by illness or injury and less often for developmental disabilities and neurologic or mental health disorders.<sup>10</sup>

Children covered in nongroup plans seldom have home health coverage. Many of these children's parents seek support from their state's Title V program for children with special health care needs and, depending on the child's condition and family income, may be eligible for gap-filling home health services. It is not unusual for families with inadequate private insurance coverage to terminate employment to gain Medicaid eligibility for their child.

Many private health insurance carriers and managed

care plans, especially those with strong case management programs, will authorize home health care when it is perceived to be a cost-effective alternative to institutionalization or outpatient treatment. However, authorizations are often for less than the services deemed medically necessary by the child's physician and the home health care agency. As with Medicaid, authorization delays and retroactive denials are common in the private health insurance industry.

## **RECOMMENDATIONS**

### **Licensure**

To ensure that eligible children have access to high-quality pediatric home health care, all states should regulate in-home services through comprehensive licensure laws that define and regulate the provision of all home health services performed by appropriately licensed and pediatric-trained personnel and all personal care services paid for by third-party payers. Until all states have effective licensure laws and regulations for home health agencies, the Joint Commission on Accreditation of Healthcare Organizations and/or Community Health Accreditation Program should enforce the credentialing requirement for contracts with all third-party payers, including Medicaid. Licensure laws should include the following requirements:

1. All home health services must be provided under a physician-approved plan of care that is reviewed every 60 days and revised as often as required by changes in the patient's condition.
2. The roles of attending physicians, home health agency clinical staff, and insurance and plan case managers should be clearly differentially defined. All agency personnel must have training to meet the needs of patients.
3. Physicians, home health agencies, third-party payers, and managed care plans should use the recommendations published by the AAP in *Guidelines for Pediatric Home Health Care*<sup>2</sup> for the purpose of determining the frequency and duration of home health services. Because few scientific studies have been conducted on the effectiveness of home health care for specific pediatric conditions, medical necessity standards should be based on professional standards of care for children or consensus pediatric expert opinion. Coverage of home health care should not be denied unless there is conclusive scientific evidence that proves that the prescribed home health care is ineffective.<sup>11</sup>
4. Licensure for unique community-based programs that compliment care in the home should be adopted to meet the child's needs and provide access to necessary health services. This includes, but is not limited

to, medical day care, respite care, educational centers, and transitional care (hospital-to-home care).

### Payment

1. Insurers and plans must adequately reimburse home health agencies, nurses, and physicians for pediatric home health visits and home care planning and oversight. Home health care payments must be increased to permit home health agencies to attract and retain appropriately credentialed clinicians and ancillary personnel for pediatric intermittent care and shift care (private duty) as well as to cover the indirect costs of clinical management and support for in-home staff. Payment adjustments must also take into account the costs associated with preparation and continuing education of nurses in pediatric competencies, intensive care, and technological skills.
2. Insurers and plans must permit physicians to bill for prolonged oversight services, telephone calls, and online consultations to ensure comprehensive and continuous care for vulnerable children when direct patient contact is unnecessary. In addition, insurers and health plans must reimburse for case management to help maintain a medical home.<sup>12</sup>
3. Payment must be offered to home health agencies, nurses, and physicians that is sufficient to enable them to deliver pediatric home health care consistent with pediatric medical standards.
4. The Centers for Medicare and Medicaid Services must conduct a comprehensive analysis of the adequacy of each state's Medicaid home health care payment rates, taking into consideration the complexity of the states' current pediatric home health care patients.
5. Payment for durable medical equipment must not be bundled into payment for visits or into prospective payment arrangements for intermittent care.
6. Payment for community-based care must be provided by Medicaid, SCHIP, and/or private health insurance companies when cost-effectiveness is evident.

### Coverage

1. Private health insurers and non-Medicaid SCHIP plans must be encouraged to offer more comprehensive coverage of home health services for children (including foster children), including private-duty nursing, home health aides, therapies, durable medical equipment, and respite care.
2. Enrollment caps and waiting periods in Medicaid and TEFRA must be reduced or eliminated for children who are medically in need of home health services.

3. Arbitrary limits on the number of days of coverage must be eliminated. Services should not be discontinued without the order of a physician.
4. Public and private third-party payers must clarify and standardize their coverage plans/benefit packages for children who need pediatric in-home services with input from the AAP, including the definitions of "medical necessity" and "home and community-based." Medical necessity must be defined to include services that assist in achieving, maintaining, or restoring health and functional capacity; are appropriate for the age and developmental status; and will take into account the specific needs of the child.
5. New and expanded funding mechanisms must be established to support respite care for families with children who have complex medical problems that require long-term home care and families who must continue to work, preferably through Medicaid and Title V. Respite care for primary caregivers must be included in all pediatric home health care benefits.<sup>13</sup> Coverage for "respite" inpatient stays must also be covered at the appropriate level of care when there are no available qualified home health professionals within the geographic area.
6. Coverage of hospice and palliative services must be available in all pediatric home health care benefit packages so that parents of terminally ill children can obtain therapeutic services for their child even though the odds of survival are minimal.
7. Early intervention services must be covered as prescribed by a physician.
8. Medical day care must be covered.

### Research

1. The adequacy of Medicare's prospective payment system for home health care should be examined as a model for financing of pediatric home health care under Medicaid and private insurance.
2. A comprehensive analysis of the adequacy of public and private payment rates for pediatric home health care should be conducted.
3. A study of the impact of inadequate access to pediatric home care should be conducted as it relates to hospital and other health care service utilization, re-hospitalization rates, costs, family stress, and family satisfaction. Also, a study should be performed to determine if access to quality pediatric home health care will reduce overall costs of care.
4. A study that demonstrates the benefits of home care in relation to the Olmsted Act, which requires states to provide community-based services to individuals for whom institutional care is inappropriate, should be conducted.



5. Support for ongoing development of pediatric home health care standards, including a definition of medical necessity, should be encouraged.

## CONCLUSIONS

Pediatric home care involves the delivery of medical care in the home to children who are ill, recovering, or disabled. It can be as simple as dressing changes or as complex as providing mechanical ventilation. The benefits of home care for children are many, including having the child cared for in the familiar surroundings of a home environment, continued access to social support such as friends and siblings, better growth and development, and less cost compared with continued hospitalization. Implementing the recommendations outlined in this statement will enhance access to high-quality pediatric home health care.

## COMMITTEE ON CHILD HEALTH FINANCING, 2004–2005

Thomas K. McNerny, MD, Chairperson

Charles J. Barone, II, MD

Anthony D. Johnson, MD

Richard Lander, MD

Richard Y. Mitsunaga, MD

Mark S. Reuben, MD

Corrine A. Walentik, MD

\*Steven E. Wegner, MD, JD

Mark J. Werner, MD, CPE

## PAST COMMITTEE MEMBERS

Jean Wright, MD, MBA

Jeff Brown, MD

## CONSULTANT

Margaret McManus, MHS

## STAFF

Lou Terranova, MHA

\*Lead author

## REFERENCES

1. Medical Expenditure Panel Survey [online database]. Household Component, Health Systems Research. Rockville, MD: Agency for Healthcare Research and Quality, Department of Health and Human Services; May 27, 2004. Available at: [www.meps.ahrq.gov](http://www.meps.ahrq.gov). Accessed June 22, 2006
2. Zafar H, Nash D. Present and future of pediatric home health care. In: McConnel MS, Imaizumi SO, eds. *Guidelines for Pediatric Home Health Care*. Elk Grove Village, IL: American Academy of Pediatrics; 2001:11–35
3. Casiro OG, McKenzie ME, McFadyen L, et al. Earlier discharge with community-based intervention for low birth weight infants: a randomized trial. *Pediatrics*. 1993;92:128–134
4. Close P, Burkey E, Kazak A, Danz P, Lange B. A prospective, controlled evaluation of home chemotherapy for children with cancer. *Pediatrics*. 1995;95:896–900
5. Fields AI, Rosenblatt A, Pollack MM, Kauffman J. Home care cost-effectiveness for respiratory technology-dependent children. *Am J Dis Child*. 1991;145:729–733
6. Laudani R. Pediatric home health care providers. In: McConnel MS, Imaizumi SO, eds. *Guidelines for Pediatric Home Health Care*. Elk Grove Village, IL: American Academy of Pediatrics; 2002: 43–52
7. Limb SJ, McManus MA, Fox HB. *Pediatric Provider Capacity for Children With Special Needs: Results From a National Survey of State Title V Directors*. Washington, DC: Maternal and Child Health Policy Research Center; 2001
8. Social Security Act, 42 CFR 435.227(a), §1902(e)(3)
9. Fox HB, Levtov RG, McManus MA. *Eligibility, Benefits, and Cost-Sharing in Separate SCHIP Programs*. Washington, DC: Maternal and Child Health Policy Research Center; 2003
10. Fox HB, McManus MA, Reichman MB. *The Strengths and Weaknesses of Private Health Insurance Coverage for Children With Special Health Care Needs*. Washington, DC: Maternal and Child Health Policy Research Center; 2002
11. American Academy of Pediatrics, Committee on Child Health Financing. Model contractual language for medical necessity for children. *Pediatrics*. 2005;116:261–262
12. American Academy of Pediatrics, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. The medical home. *Pediatrics*. 2002;110:184–186
13. Thurgate C. Respite for children with complex health needs: issues from the literature. *Paediatr Nurs*. 2005;17(3):14–18