

# Health Care *for Children*

*What's Right, What's Wrong,  
What's Next.*

Edited by

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United  
Hospital Fund

Maternal and child health practices: Problems, resources and methods of delivery. Springfield, IL: Charles C Thomas.

Shonkoff JP, Meisels SJ. 1990. Early childhood intervention: The evolution of a concept. In: Meisels SJ, Shonkoff JP, editors. Handbook of early childhood intervention. New York: Cambridge University Press.

Stanton N, Anderson OW. 1948. EMIC (emergency maternity and infant care): A study of administrative experience. Bureau of Public Health Economics, Research Series No. 3. Ann Arbor, MI: School of Public Health, University of Michigan.

Task Force. 1982. Report of the task force on opportunities for women in pediatrics. Evanston, IL: American Academy of Pediatrics.

Task Force of Health and Human Services, Public Health Service. 1987. Children with special health care needs, campaign '87. Iowa City, IA: National MCH Resource Center.

Wallerstein J, Bielek RF, MacQueen JC, Blackman JA. 1996. Mosby's resource guide to children with disabilities and chronic illness. St. Louis: Mosby-Year Book.

Winter. The Network News; 8:2. Elk Grove Village, IL: American Academy of Pediatrics.

Winter. The American Pediatric Society, The American Academy of Pediatrics and the Children's Bureau: 1944-1945. In: Pearson LA, with assistance of Brown AK. The centennial history of the American Pediatric Society, 1888-1988, pp. 86-9. American Pediatric Society.

## 6

### *Health Services for Children and Adolescents: A "Non-System" of Care\**

Holly Grason and Madlyn Morreale

HEALTH SERVICES FOR CHILDREN in the United States are characterized by fragmentation, not organization. The "non-system" of health care comprises a mix of public and private care, largely divided along the lines of population-based programming under the aegis of the public sector and medical care for individuals provided within the market-driven private sector.

While the pervasive forces within U.S. culture emphasize individualism, market economics, and local and state sovereignty—and therefore private sector medical care—such care is only one component of the system needed to address the health needs of children and adolescents. Socioeconomic, environmental, psychosocial, and developmental aspects of child and adolescent health require a multidisciplinary and multisector approach, with a number of interventions—such as efforts to reduce alcohol consumption or exposure to lead—implemented both at the individual treatment level and on a population basis. Neither public nor private sector efforts alone have been sufficient to address the broad spectrum of child and adolescent health care needs, and policymakers face significant challenges in developing a coordinated and integrated system of care for this population.

In this chapter, we argue that children and adolescents have unique health service needs that require a comprehensive and coordinated array of medical care, linked with community-based services. We then chart the

\*Madlyn Morreale's work on this chapter was partially funded by the Prevention Centers Program, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention.

evolution of the public sector response to child health needs and explore, in brief, how and why we have the system we do. We demonstrate that while the United States has elements of the full spectrum of services needed to address the specific health needs of children and adolescents, these components are not organized as a cohesive system. We further characterize the fragmentation of health care delivery for children and youth as they relate to three significant factors. We next discuss "wraparound" approaches to linking service components for children and youth in this country, and note models of systems seen in other industrialized countries as well as in services for the elderly in the United States. In conclusion, we discuss the implications of current trends in the organization of health services—such as evolving managed care strategies in the private sector and the move to consolidation in the public sector—for efforts to improve the manner in which children and adolescents are served.

### Unique Characteristics of Child and Adolescent Health

As described in chapter 1, children and adolescents have health service needs distinct from adults', requiring different types of prevention, diagnosis, and treatment strategies. Jameson and Wehr (1993) have argued for a special standard of medical necessity for children with respect to clinical services, based on children's developmental vulnerability in the context of rapid growth and development, their dependency on adults and social institutions for both financial and nonfinancial support in accessing health care, and the differential epidemiology of disease whereby health problems in children and adolescents differ in prevalence and scope from illnesses in adults. Similar arguments can be made for special standards for health care system structures and functions for children and adolescents. Such standards would recognize the extent to which development influences the medical needs of children and the special opportunities to avoid or reduce the potential impact of disease or disability through early, aggressive, and ongoing prevention.

These standards would also recognize the importance of flexibility. Although an adult's health profile may stabilize for many years, children's medical needs are constantly and often rapidly evolving as children grow and develop. Health and development are intertwined in complex ways that have potential long-term impact. For example, even moderate injuries resulting from the use of child passenger restraints can cause irreversible develop-

mental and cognitive impairments with long-term costs and consequences. Lead poisoning, particularly as it is linked to mouthing behavior in young children, can cause irreversible developmental and cognitive impairments.

The dependency of children and adolescents, which makes them a uniquely vulnerable population, also has implications for the structure of health systems. For young children, preventive initiatives need to be implemented indirectly through parents, child care providers, protective environmental legislation, and the social institutions on which children depend. As children move into adolescence, the extent of their dependence lessens, but it does not disappear entirely for some years. Special skills are required of clinicians who serve children and adolescents in establishing partnerships with others in order to implement interventions.

The unique characteristics of adolescence as a discrete life stage provide an apt example of how biological and social as well as environmental contexts interact in complex ways to pose threats to health that require linked medical and community-based care. For adolescents, the biological changes introduced by puberty are joined with newly emerging risk-taking behaviors that may result in a variety of preventable morbidities and mortalities, including injuries due to violence and motor vehicle accidents; the consequences of unprotected sexual behavior; and the deleterious impact of alcohol, tobacco, and other drug abuse. The risk factors for these issues are strongly associated with complex environmental and social influences that are unlikely to be resolved in visits to medical clinicians. Igra and Millstein's (1993) analysis of 1990 data from the National Ambulatory Medical Care Survey found that screening for behaviorally related health conditions occurs in less than half of physician office visits by adolescents. However, increasing the delivery of these services during office visits alone may be insufficient. Adolescents' increasing reliance on peer norms and the relative importance of the environmental and social context compared to the biological context mean that interventions may be most effective if fashioned for community settings.

Thus, a health services system predicated on adult health care needs—relatively few and unchanging health problems generally treatable in a traditional clinical setting—is insufficient for meeting the health needs of children and adolescents. Drawing on these concepts of development, dependency, and differential epidemiology, effective health systems for children and adolescents demand:

- medical care that is responsive to developmental factors and emphasizes prevention;
- practitioners with special knowledge of pediatrics and adolescent health, including medical specialties;
- special strategies for intervention that include interactions with caregivers—parents, child care providers, and school staff—as well as peers during adolescence; and
- an array of interventions that extend beyond office- or clinic-based medical care, and include other health, social, and educational strategies.

A balanced focus on population-based prevention and community-based interventions as well as coordination of health services delivery along a number of continuums is needed. Inherent in this view is a partnership between the pediatric practitioners who provide health supervision and medical care to individual children and adolescents, and the public entities that guide, develop, and organize the planning and delivery of complementary population-based health services such as screening, disease control, environmental interventions, nutrition programming, and health education. A brief look at the evolution of the current system, however, demonstrates that such principles have not consistently guided the development of the U.S. health care system for children and youth.

#### **Brief History of the Development of Public Health Programs for Children and Adolescents**

The evolution of the current system has been influenced by economics and politics as much as by the assessed health needs of children and adolescents. The child health problems that evoked national concern in the late nineteenth and early twentieth centuries were related primarily to hygiene and infectious diseases. Because many of these problems were concentrated in densely populated urban areas, the health of mothers and children became the concerns of the then newly organized city public health agencies (Lesser, 1985). A linkage between health services and social welfare concerns coalesced in the creation of the Children's Bureau in 1912 (see chapter 5 for full account). Charged with a broad mandate to investigate and report on critical children's health and welfare concerns, including infant mortality, orphanages, juvenile courts, child labor issues, and child health and injuries, the Bureau adopted a population approach to child health concerns.

In 1921 the Maternity and Infancy Act, or Sheppard-Towner Act, was passed to provide resources for state health agencies to establish and improve health services for women and children. When this legislation expired in 1929, a service infrastructure had been developed in most states, providing a foundation for the national Maternal and Child Health (MCH) program established in 1935 through Title V of the Social Security Act. Under Title V, states received formula grant funds to establish units to develop and oversee clinical preventive health services for the broad population of mothers and children, and treatment services for "crippled children." Case finding and a comprehensive multidisciplinary approach to service delivery were emphasized. In addition to service provision, the Act stimulated the development of a system of high-quality services with a mandate to "extend and improve services," and a requirement that state plans be developed.

This governmental response to child health recognized: the need for 1) prevention services organized on a population basis, 2) state planning and gap-filling responses to the maldistribution of pediatric providers, especially in rural areas, and 3) a public response to health problems requiring highly specialized services not adequately addressed by organized medicine, such as specialized care for "crippling conditions" resulting primarily from poliomyelitis. For many years, the federal-state Title V MCH partnership was the predominant means by which public, and to some extent private, health services for women and children were organized. The scope and nature of health services in both sectors changed little between the late 1930s and the early 1960s.

Some 30 years following the creation of Title V, the "Great Society" agenda of the Kennedy and Johnson administrations spurred the development of health, social welfare, education, and economic opportunity programs for children and families. Between 1963 and 1965, a variety of programs were launched, including the Maternal and Infant Care projects, Comprehensive Children and Youth projects, and the Office of Economic Opportunity Neighborhood Health Centers. In 1965, Medicaid (Title XIX of the Social Security Act) and its Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program were enacted. As a result of these federal initiatives, public funding streams and program authority for services began to bypass state government, and the threads of the state-based infrastructure for planning, organizing, and monitoring the system began to unravel. In the 1960s, the growth of categorical funding for special programs was fueled by a number of complex and interacting forces, including the civil

rights movement and consequent distrust of states' abilities to address important social problems. In addition, significant advances in medical technology provided new venues for treatment for highly vulnerable, small subsets of the child population (for example, children with cardiac conditions and low-birthweight infants).

Small but vocal constituencies—of both providers and consumers of health care—began to advocate and ultimately compete for resources to support their preferred new programs. Moreover, as the national economy began to weaken relative to the boom of the post-war years, incremental or sequential public health programming approaches developed as the most viable means by which to secure congressional approval of public funding requests. Over the next 15 years, additional expansions in categorical services for special populations and problems, such as for family planning, dental care, child development (through the Head Start program), and nutrition (through the Special Supplemental Food Program for Women, Infants and Children, or WIC), continued, and little or no attention was paid to the relationships among programs. Similar trends in child welfare and education program development occurred during this period.

In the 1970s and early 1980s, the Nixon and Reagan administrations sought significant change in governance through a "New Federalism," which attempted to return authority to states. Though not as far reaching as originally proposed (Combs-Orme and Guyer, 1992), the resulting block grant approach initially produced significant reductions in resources for public services and all but eliminated federal agency responsibilities for program administration. While some child health program consolidation occurred with the creation of the MCH Services Block Grant, the federal role in organizing the health services system for women and children was diminished by virtue of lack of authority, funding, capacity, and, at times and places, credibility.

In short order, however, the consolidation goals of the Nixon and Reagan administrations were eroded as Congress responded to the concerns of national advocacy groups about the lack of accountability of block grant programs by legislating earmarks and set-asides for categorical activities. Concurrently, fiscal constraints and conservative political trends demanded that reforms be implemented incrementally rather than comprehensively. These factors led to the reemergence of a categorical approach to health services funding and programming. Medicaid expansions and enhancements, although significant, were implemented through multiple annual changes

for discrete subpopulations and services. More recently, the emergence of new morbidities, such as AIDS, youth violence, and other risk-related morbidities, contributed to the development of new categorical initiatives including the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act, pediatric AIDS programs, Children of Substance Abusers Act, Program for Pregnant Substance Abusing Women and Their Infants, and fetal alcohol syndrome programs administered by the Centers for Disease Control and Prevention. In addition, new categorical programs were established for lead poisoning prevention and immunization services, which were believed to have been neglected by states when incorporated into block grants in 1981. The early 1990s also brought significant expansions of school health centers as a source of health care for children and adolescents.

#### **The Current Context of Child and Adolescent Health Services**

And so today, health and related care for children is provided through multiple and uncoordinated service delivery structures, which evolved from several decades of separately enacted pieces of legislation aimed at filling gaps in service availability and in access to personal health services through a variety of financing mechanisms and through the provision of services such as outreach or transportation. In addition, legislation has created public health programs to add services not otherwise provided within the context of private-office pediatric care.

#### **Mix of Public and Private Sector Personal Health Care Delivery**

Child and adolescent health services are delivered in public health departments, private physician offices, community health centers, and other non-profit community agencies, schools, and hospitals (Table 6.1), with no centralized source of information, intake, or coordination at the service delivery level. Particularly problematic over the years has been the geographic maldistribution of practicing pediatricians, with far too few in rural and inner-city areas (Perloff, 1992; Schroeder, 1992). The government response to resulting access problems has been the establishment of personal health services in local health departments, community/migrant health centers, and more recently, school facilities. Notwithstanding the broad array of potential providers, more than 12 percent of all children reported having no source of routine care in 1988 (National Center for Health Statistics, 1988).

Further complicating this picture, children's involvement with the health services system is rarely limited to only one source of care. Most children and

Table 6.1  
Source of Routine Health Care for Children and Adolescents  
United States  
1988

Age	No source of routine health care	Physician office/private clinic <sup>1</sup>	Community, neighborhood, or other family health center <sup>2</sup>	Hospital outpatient clinic	Other source <sup>3</sup>
0-17	12.1%	73.4%	5.4%	4.1%	5.1%
0-11	10.2	74.3	5.2	4.2	5.5
12-17	16.2	71.5	3.5	3.8	4.6

Source: National Center for Health Statistics (1988).

<sup>1</sup>Includes HMO/prepaid group practices.

<sup>2</sup>Includes migrant, and rural health centers, which each is reported as a source of routine care for less than 1 percent of children and adolescents.

<sup>3</sup>Includes company, school, or other clinics; walk-in emergency care centers; home; or other place. Less than 1 percent of children and adolescents (in each age group) reported using each of these sources.

adolescents obtain care in the private pediatric sector, and interact infrequently with publicly funded health services. Their contact with public health services may be limited to seeing a school health nurse for hearing or vision screening, or for acute care because of a school playground injury. Another group of children, however, receives care from the private sector, but because of a particular condition or problem, has more extensive interactions with the public system. For example, children with chronic health impairments may receive medical attention in specialty clinics administered by state programs for children with special health care needs (Title V/MCH) or in school settings. There is also a group of children who are quite intensely involved with the public sector. These children and youth often live in low-income households in disadvantaged urban or rural areas where private care is scarce and unaffordable. These children and youth therefore rely heavily on the public sector for needed care and are among the most intensive users of services. Nevertheless, children who routinely use a broad array of both public and private services represent a minority of the population.

#### Mix of Public and Private Insurance Strategies

Insurance coverage patterns for children and adolescents mirror the mix of private and public health service delivery. Most children are covered through dependent care coverage of their parents' employer-based health

plans (Employee Benefits Research Institute, 1996; U.S. General Accounting Office, 1996a). Trends in health care coverage over the last decade, however, show a decline in employer-based coverage for children and adolescents (Newacheck et al., 1995a; Rosenbaum, 1992; U.S. General Accounting Office, 1995b, 1996a). Children whose parents are unemployed, as well as those whose parents' employers do not include coverage for dependents in their benefits packages, must rely on public coverage. Neither employment nor low income guarantees insurance coverage, however. As a case in point, approximately two-thirds of uninsured adolescents live in families with incomes above the poverty level (National Research Council, 1993).

Further, underinsurance (limitations in benefits) has long been a problem for children covered under traditional employer-based indemnity insurance plans. Gaps in employer-subsidized benefits persist, both for preventive care, including well-child visits and immunizations, and for specialized care, such as mental health and substance abuse treatment for adolescents and medical and habilitative specialty care for children with chronic health impairments (Elster et al., 1993; Hughes et al., 1995; Mannus and Hertz, 1995; Short and Banthin, 1995; U.S. Congress, Office of Technology Assessment, 1991). Thus, even when children are insured through their parents' employer-based coverage, they may need publicly financed coverage and/or services.

Medicaid and its EPSDT component represent the single most important source of financing and programmatic guidance for public child health programs. (EPSDT requires states to periodically screen Medicaid-eligible children under 22 years for illnesses, abnormalities, or treatable conditions, and to refer them for definitive treatment.) Originally, Medicaid and EPSDT served only very low-income women and children. Expansions of the Medicaid program in the 1980s, however, weakened the link between welfare and Medicaid, first with legislation allowing for optional extension of coverage to pregnant women and infants who were not receiving Aid to Families with Dependent Children (AFDC), and ultimately with a mandate in the Omnibus Budget Reconciliation Act of 1989 (OBRA '89), to extend coverage to pregnant women and infants to 133 percent of the federal poverty level, and to young children in families with incomes under 100 percent of the federal poverty level. OBRA '89 also provided important expansions to the EPSDT program, requiring states to provide any federally reimbursable service that is "medically necessary" to diagnose or treat a problem that is identified in the screening, regardless of whether that service is included in the state's Medicaid plan. Eligibility for children over age

6 was subsequently phased in, one year at a time, so that (assuming no changes in federal policy) all poor adolescents under age 19 will be covered in the year 2001 (Omnibus Budget Reconciliation Act of 1990).

These Medicaid expansions, coupled with state public and private child health insurance programs in some states, have mediated the extent of uninsurance (Newacheck et al., 1995a; U.S. General Accounting Office, 1996a, 1996b). By 1994, more than 16 million children and adolescents were covered under Medicaid, or about 23.2 percent of the population under 18 years of age (Employee Benefits Research Institute, 1996). Eligibility for Medicaid, however, remains complex, with a myriad of age, income, and medical criteria for enrollment.

**Uncoordinated Public Sector Programming**

For those children and adolescents who rely on public programs to meet their health needs, families must sort through many small and often inconsistent rules and procedures to find their way to the frequently overlapping public programs and services that might assist them. All too often, inconsistent and rigid eligibility requirements confound or preclude access to care. Efforts of policymaking bodies, public program administrators, and the public to address children's needs are similarly thwarted by the sheer numbers of programs, as well as by the complete absence or the complexity of linkages among them.

Federally legislated child health programs implemented today represent a mix of income-based entitlement programs (e.g., Medicaid and EPSDT), quasi-entitlement programs (e.g., WIC), categorical population or disease-specific programs (e.g., immunization, pediatric AIDS, lead poisoning, health care for the homeless, and family planning programs), age-specific entitlement programs (e.g., early intervention services for infants and toddlers with disabilities), as well as "gap filling" formula grant funded programs (e.g., Title V prenatal and child health services, and categorical grants to localities for community and migrant health centers. Health services also are embedded in entitlement and categorical programs for education (e.g., special education and school health services) and social services (e.g., Head Start, family preservation programs). This array is even more complex when one looks beyond to income maintenance, employment, housing, and justice programs. By and large, this body of federal authorizing legislation and its implementing regulations are not coordinated (National Commission on Children, 1991; Reinhold and Frank, 1993; U.S. General Accounting Office, 1995a).

More recent legislative initiatives to improve services to children, such as those found in the Child and Adolescent Service System Program and the Individuals with Disabilities Education Act early intervention program for infants and toddlers, attempt to redress some of these problems through a "systems" focus, incorporating requirements for interagency coordination of policy development, planning, service provision, and financing. However, states and localities are now grappling with the overlap among complex systems as well as the overlap among complex programs.

**Service System Snapshots**

Although linking individual (private sector) and population-based (public sector) care makes sense in terms of meeting child and adolescent needs, it is clear that the current system has evolved in response to a host of other influences and rationales that have undermined the goal of developing a coherent and organized system of care for children and adolescents. As described below, the services available to children and families depend on a variety of factors such as age, area of residence, and definition of need (health or developmental risk and/or impairments, financial status, etc.), and fail to meet the needs of many families in many ways.

Understanding the scope and complexity of service programs, eligibility criteria, and the pathways to access can be a formidable challenge. While a child's needs may remain constant, changes in family status or age may lock a child out of needed services; conversely, a child may remain ineligible for needed services despite changing or intensifying needs. Paradoxically, the complex array of services may result in a child being technically eligible for many similar programs but unable to get help because limited program funding has resulted in long waiting lists, or because programs are completely absent in many localities (U.S. General Accounting Office, 1995a). To illustrate these points, three scenarios are outlined below.

**The Story of Kelli: How Changes in Income Status Impact Service and Program Eligibility**

*Kelli is four years old. She lives with her mother, who has never worked outside the home. Kelli's parents divorced two years ago. Kelli's father has been living apart from the family since her birth without providing child support or other financial assistance. Kelli and her mother recently lost their eligibility for dependent coverage through her father's employer-sponsored health insurance. Kelli has not seen a medical provider in the past year. Her mother*

Table 6.2  
 How Income Status Impacts Service/Program Eligibility: The Case of Kelli

	Program or service	Program/service orientation or function	Comments
Kelli while her mother has no earned income	Private physician care	Medical services.	Such care is likely to be paid for by Medical Assistance (see below). Local physicians, however, may limit the number of Medical Assistance patients they see.
	Temporary Assistance to Needy Families (TANF)	Income support, with work requirement that provides assistance with child care expenses.	Each state sets eligibility criteria. TANF benefits are unlikely to raise a family's income to more than 50 percent of the federal poverty level
	Medical Assistance	Payment for medical care for very low income individuals/families, and those with disabilities.	As long as Kelli and her mother meet 1996 eligibility criteria for welfare, Kelli will be eligible for comprehensive preventive, primary, and specialty care through EPSDT.
	Head Start	Center-based developmental services to low-income children under age 6: primarily serves 3- and 4-year-olds. Health and screening and referral, immunizations, and nutrition are also provided.	Kelli is likely eligible to attend a Head Start center as long as one operates nearby and does not have a long waiting list for enrollment.
Kelli after her mother obtains a minimum-wage job	WIC	Nutritional supplements (food packages or vouchers) to pregnant and postpartum women, infants, and children through age 4 who are at risk of inadequate nutrition.	Kelli is unlikely to be eligible unless she has lead poisoning, anemia, or another health condition that puts her at high nutritional risk.
	Health care services	Local health departments, community health centers, and/or hospital clinics may be available to provide preventive and primary care for Medicaid beneficiaries and persons without insurance.	Kelli's mother will lose eligibility for Medical Assistance within a year of starting her new job. She is unlikely, however, to obtain private health insurance through her minimum-wage job.
	Head Start	Same as above.	A significant increase in her mother's income may make Kelli ineligible for program services.
	Child Care Block Grant	Infrastructure development to improve availability and quality of child care; some assistance for payment.	Kelli's mother is probably eligible for help in finding and paying for child care. This care will need to be coordinated with Head Start services in terms of hours and transportation.
	Earned Income Tax Credit (EITC)	"Refundable" tax credit to subsidize earnings of low-income families.	Kelli's mother may receive between \$1,000 and \$2,000 additional income through this program.

has relied on assistance from her church and public programs for groceries and income support. As a condition for receiving welfare payments, Kelli's mother must participate in job training courses. She has had trouble finding child care services that she can afford while attending these courses.

The health and social support services available to Kelli and her mother will vary depending on Kelli's mother's income and employment status (Table 6.2). Within a year of Kelli's mother receiving a minimum wage position, she and Kelli will lose health coverage as a result of employment. If Kelli is able to participate in Head Start, some health services may be available to her through that program. However, unless Kelli and her mother live near a community health center, or unless a private pediatrician will provide care without compensation, Kelli's health care may be available only at the local emergency room.

### *The Story of Naomi: How Age Impacts Service Eligibility*

Naomi was born with spina bifida, a neurological condition characterized by incomplete closure of the spinal cord, with consequent paralysis of her lower extremities, and neurogenic bladder and bowel. Naomi was shunted soon after birth in an attempt to prevent hydrocephalus and related mental retardation. Over her lifespan, Naomi will need surgery to close the spinal column and for shunting. She will also need bracing and other physical and occupational therapy interventions related to her paralysis, skin care, urologic monitoring, bowel training, monitoring for scoliosis, and special attention to the Naomii's parents both work, although her mother works only part-time so that she can devote the extra hours and energy needed for Naomi's daily care. Her family has health insurance through her father's employer, although the coverage package is limited as the company he works for is small, with a limited profit margin to allocate to the employees' health benefit package.

The services that Naomi needs and that she and her family are able to access will differ markedly depending on her age (Table 6.3). The availability of services depends largely on the extent to which Naomi's medical condition impacts her cognitive development and her ability to function independently (age-appropriately) at various ages. It is also determined by her family income, program rules in her state of residency, and the variable application of parental resources to the determination of eligibility for public programs.

Table 6.3  
How Age Impacts Service Eligibility: The Story of Naomi

Program or service	Program orientation/function	Comments
Naomi at 2 years	Private physician care	Medical services.
	Title V MCH Block Grant Program for Children with Special Health Care Needs (CSHCN)	Care/service coordination for the child/adolescent; financing for medical care not covered by insurance; administration/funding for multidisciplinary specialty services (clinics).
	Part H, Individuals with Disabilities Education Act	Developmental/early intervention and special education services (center or home-based); services planning and coordination.
	Child Care Block Grant	Infrastructure development to improve availability and quality of child care; some assistance with payment.
		Most routine services are covered by insurance, but specialty care may not be. Immunizations are not covered under parents' health plan.
		Because this is a block grant, not an entitlement program, federal/state funds are capped. Naomi's eligibility depends on how medical and financial eligibility is defined in her state of residence.
		Free appropriate public education is provided if Naomi meets state's criteria for developmental delay, risk, or disability. Only available to age 3.
		Naomi's family may receive assistance until she is 13 years old, depending on state rules implementing federal requirements related to children with disabilities.

Table 6.3  
How Age Impacts Service Eligibility (cont.)

	Program or service	Program orientation/function	Comments
Naomi at 19 years	Private physician care	Medical services.	Naomi may lose coverage under her parents' policy unless she is in school.
	Title V MCH Block Grant Program for CSHCN	Same as above.	Naomi may receive services as above, but only those Medicaid does not cover. She may be ineligible, depending on age cut-offs in her state of residence.
	Supplemental Security Income (SSI)	Income support for low-income disabled adults.	Naomi may be financially eligible because family income ceilings no longer apply after age 18. Her eligibility also will depend on the severity of her condition and her potential employability.
	Medical Assistance	Payment for medical care for very low-income individuals, and those with disabilities.	Naomi is now categorically eligible by virtue of SSI eligibility. Comprehensive EPSDT no longer applies.
	Food stamps	Coupons redeemable for retail food purchases.	Naomi is now eligible by virtue of SSI eligibility.

### *The Story of Peter: How Living Situation Affects Receipt of Services*

*Peter is 16 years old and has a history of alcohol and substance abuse and mental health problems associated with the ongoing physical and emotional abuse he experiences at home. His parents live in a small, rural town and their employer-sponsored health insurance does not cover mental health or substance abuse services for dependents. Peter does not know this, however, because he is reluctant to seek assistance. He is unaware of any publicly supported service in his community. Peter's school performance has been satisfactory until this year, but now he is considering dropping out of school and running away from home.*

The health-related services available to Peter depend on whether he remains at home or runs away, as well as on where he and his family live, his parents' income, whether he becomes a ward of the state, the availability of publicly financed categorical programs or privately funded care, and Peter's knowledge of these resources (Table 6.4).

These brief stories illustrate a number of important limitations of the current system of health and social support services for children and adolescents. In each story, change in only one variable (age, residence, or income level) resulted in dramatic changes in access to services, even when the need for these services changed very little. In reality, the lives of children, youth, and families are even more dynamic, and multiple variables are likely to change over the course of a child's life, making efforts to coordinate continuous access to services difficult for both families and providers. Moreover, the scope of these and most children's needs extends far beyond what health care providers alone can provide, regardless of the adequacy of insurance coverage.

### **Efforts to Link Private and Public Sector Care**

Notwithstanding this bleak picture, some partnerships have succeeded in enhancing and extending private office medical care. Enhancements to Medicaid and other programs enacted in the mid-1980s and early 1990s provided important new venues for public-private partnerships. For example, when Medicaid extended financial access to private sector obstetrical and pediatric care, limitations in the capacity of the market-driven private sector to meet the needs of the Medicaid-eligible population became increasingly evident and documented (Hill, 1992; Lewis-Idema, 1988; Perloff, 1992). These limitations included the lack of sufficient providers to absorb additional Medicaid beneficiaries into private practices, low reimbursement

**Table 6.4**  
**How Residence or Living Situation Impacts Service Eligibility: The Story of Peter**

	<b>Program or service</b>	<b>Program/service orientation or function</b>	<b>Comments</b>
Peter living at home	Physician care	Medical services.	Peter may get care for acute medical problems from his family doctor, with payment made through his parents' insurance.
	Medical Assistance	Payment for medical care for very low-income individuals/families and those with disabilities.	Peter is not eligible because of family income. In most cases, an adolescent must become a ward of the state (through the child welfare or juvenile justice system) before he/she becomes eligible for Medical Assistance. <sup>a</sup>
	Substance Abuse Prevention and Treatment Block Grant	Prevention, treatment, and rehabilitation activities related to alcohol and other drugs, including inpatient and outpatient alcohol and drug detoxification and counseling.	The availability of services depends on the locality and the priorities of state planners. Peter is unlikely to know whether these services are available in his community unless he actively seeks assistance.
	Child Welfare Services	Services for abused, neglected, homeless, and troubled youth under age 21 and their families, including preventive interventions to keep children in their homes, family reunification, and alternative placements.	These services are administered by states and counties and have no income requirements. Peter's ability to access these services depends on his knowledge of their availability and his willingness to report the abuse he experiences at home and on the level of services in each area.
	Child and Adolescent (Mental Health) Service System Program	Services for children and youth aged 0-22 years who are at risk for mental health and emotional or behavioral disorders.	The availability of services depends on the locality and the priorities of state planners. Peter is unlikely to know whether these services are available in his community unless he actively seeks assistance.
Peter living on the streets	Runaway and Homeless Youth Program, Basic Centers	Short-term emergency shelter, counseling, family reunification, direct outreach, and linkages with community agencies that provide other support services.	Peter's access to basic centers depends on his knowledge of their existence and whether one exists in the community to which he has run away. The total number of basic centers in 1995 was 366.
	Transitional Living Program for Runaway and Homeless Youth	Mental and physical health care, housing assistance, job placement services, and educational and career training for youth aged 16-21 years who cannot be reunited with their families.	Peter's access to transitional living services depends on his knowledge of their existence and whether one exists in the community to which he has run away. The total number of programs in 1995 was about 75.
	Health care services	Local health departments, community health centers, homeless centers, or organizations receiving other public or private funds.	Unless Peter becomes Medicaid-eligible, his care will likely be provided without payment. Providers are reimbursed for services to non-paying patients through categorical grants, private donations, and other unstable sources.

<sup>a</sup>The process of becoming a ward of the state varies by state. Typically, there must be either voluntary placement by the parents or substantiated abuse or neglect that results in court-ordered placement in the child welfare system. Once a child or adolescent is in the child welfare system, most states will provide Medical Assistance, regardless of the family's income.

rates, and inconsistent duration of client eligibility, which created uncertainty about payment for services provided. In addition, pediatric clinicians practicing in communities became aware of limitations in their ability to provide the full array of interventions and support needed by low-income populations. To compensate for these gaps in the private sector, the public sector offered enhancements to standard medical care through wrap-around services such as outreach, follow-up for care recommendations provided during office visits, case management, additional nutritional and social work counseling services, home visiting, and health education (Association of Maternal and Child Health Programs, 1991; Balla, 1995; Bell and Slinkin, 1993; Buescher et al., 1991, 1993; Hill, 1992; Hill and Bennett, 1990; Hill and Breyel, 1989, 1991; U.S. General Accounting Office, 1990).

While promising, these new public-private partnerships evolved haphazardly, often relying on the availability of unstable funding sources, and with no systematic organizational focus nationally. Our collective failure as a society to enact universal national health care legislation diminished the hopes of many child health advocates that a remedy would emerge in this century. The growth of managed care and integrated service networks within the health industry, however challenging in the intensity and magnitude of the changes they bring, may provide new opportunities to promote systemwide approaches that make sense for families and that adequately meet the full spectrum of child and adolescent health needs.

### **Integrated Models**

While the United States may have begun to fashion an organized system approach earlier in this century with the creation of the Children's Bureau as a locus for national planning and oversight and the development of the state-federal MCH partnership program in Title V, this review illustrates the need to address the well-intentioned but haphazard manner in which health services for children and adolescents evolved over the course of this century.

Comparative studies of health systems in other industrialized countries that have organized primary care systems that link private medical and public population-based services reveal the potential for improved health outcomes for the population ("Child Health," 1990; Starfield, 1991; U.S. General Accounting Office, 1993; Williams and Miller, 1991). France, Belgium, Japan, and the Scandinavian countries all have fashioned approaches to maternal and child health services that universally assure women, chil-

dren, and their families have access to preventive and curative personal and population-based health services. Public sector roles in these countries include disseminating information about health and development, outreach, providing community-based preventive services such as health screening and home visiting, and tracking and follow-up to help secure adequate health care and to promote parental participation in assuring that children receive appropriate care. Private sector physicians provide medical care for acute and chronic conditions. This is accomplished with a governmental locus of accountability on the national, regional, and/or community levels. To date, however, other countries' health systems models have not been seriously considered by most U.S. policymakers, by leaders in the private sector insurance industry or in the medical professions, or by the general public.

Models exist in this country as well. Analysis of the design of services for the elderly in the United States reveals apt policy and program design lessons for child and family health services. The Older Americans Act (OAA) establishes a high-level, visible national locus for information, policy development and coordination, advocacy, research, demonstration projects, and professional training. The OAA also provides the legislative structure for a uniform consolidated program of comprehensive, community-based planning, and preventive and social services that complement the medical care financing and income support provided to the elder population through Medicare and Social Security entitlements (Grason and Guyer, 1995b).

### **Organizing Care for Children and Adolescents in Ways That Make Sense—Building the Foundation for the Twenty-first Century**

This review shows a history of public sector concern and private sector interest in addressing child and adolescent health needs. The private sector insurance and medical care provider responses that have evolved can address many, but not all, of the primary health needs of the majority of children and adolescents. However, in the absence of universal health care coverage, the public health safety net of publicly funded clinics and programs is needed to provide care for the most vulnerable, including those who are uninsured or underinsured. Ongoing attention to health system planning to assure capacity where the market does not develop (particularly in rural and inner-city areas) also is clearly indicated.

Population-based health services and activities—fundamental to addressing health education and promotion, environmental interventions, and

linkages among health, education, and social service professions and programs—also must be incorporated into a systems approach to improving the health of all children and adolescents. Enhanced wraparound health services and outreach to address underutilization of appropriate preventive and primary health care will continue to be important, particularly for the most vulnerable segments of the population—members of young families in poverty, children and youth with chronic and disabling medical and physical conditions, and those who are culturally and/or socially isolated.

Much has been written about the need to provide coordinated and comprehensive care for children and adolescents, both at the policy level and from the perspective of individual service providers. Increasingly, a systems approach has been advocated for communities, where integrated networks of providers serve children and families by linking across sites and with non-health service providers, and by blending public and private sources of funding (Hayes et al., 1995; Kahn and Kamerman, 1992; Kizner and Page, 1996; Newacheck et al., 1995b; Office of Inspector General, 1991). Moreover, at this juncture an increasing proportion of populations who are publicly insured are receiving health services through private sector managed care entities and integrated service networks. As the private sector medical profession and the health insurance industry become more organized and embrace greater accountability for enrolled populations, opportunities exist to consider new ways to blend private sector medical care with population health. Further, political support to consolidate public programming, although raising concerns about the potential erosion of financial resources and entitlement services, provides opportunities to move forward in a number of ways.

First and fundamental to assuring the health and well-being of children and adolescents is adequate funding. Health insurance coverage equal in scope to that provided for the elderly population should be universally available to children and adolescents. In addition, support for population-based public health and related community-based services must be better balanced with support for clinical medical care. Access to public programming for prevention and support services, so critical to health during this early stage of the lifespan, should not be dependent on where a child or teenager resides.

Second, responsibilities for preventive services must be sorted rationally among clinical medicine and public health. Questions related to the extent of preventive and supportive care—such as nutrition services, counseling,

and case management—that can reasonably be provided in clinical versus public health settings need to be answered, and consensus established systemwide.

Third, delineation of roles and responsibilities for health promotion and supportive services—such as wraparound and enabling services including outreach, transportation, and translation services—among public health and organized medical care is needed. Geographic regions and communities must determine how responsibility for the health of populations will be shared, and how public and private health entities will work together to assess and address population-based prevention issues, particularly educational and environmental interventions. Greater linking of individual private sector clinicians, physician group practices, and hospitals under administrative umbrellas of managed care organizations should facilitate these processes in that there will be fewer but larger and more well-defined private sector providers to assume responsibility in negotiations.

Fourth, rational realignment of the public programs that serve children and adolescents is needed to promote access to the full spectrum of services needed by individual families. Such reorganization needs to occur both at the community level, through community-based planning and service and program restructuring, as well as through legislative changes at the national and state levels. The general trend in the political arena to consolidate public programming through block grants can provide the basis for such restructuring—but only if planned with a comprehensive, long-term view and implemented incrementally to allow for systematic monitoring of impact and feedback guiding future steps. We cannot afford for important supports for children and youth to be lost through hasty reconstruction. As elements of such efforts, structural changes at the local level need to assure centralized information and entry into public programs, as well as systems that allow information to move among multiple providers (public programs and private sector medical providers and managed care organizations) serving a single child or teenager while guarding sensitive and confidential information.

Finally, of critical importance in these evolving systems changes is advocacy for children and adolescents, who as a population are physically, socially, economically, and legally dependent on adults. Societal responsibility for the health and well-being of children and adolescents must be implemented at both the clinical care and governmental levels. Special standards of care for children and youth must be established for managed care entities and integrated service networks: system structures predicated on adult

needs alone cannot appropriately address the health needs of our youngest citizens. Further, assuming that managed care strategies will be widely implemented with a focus on controlling expenditures, tools of government—legislation, regulation, contracting specifications, and external review—and auditing of private sector services—should be used to assure that MCH-specific criteria are met and that the focus on cost savings does not harm children and adolescents (Grason and Guyer, 1995a).

This work will not be easy, but few challenges of significant importance to our country are. Implementing this vision will require a societal commitment to children not observed to date, but not, we believe, impossible if our country truly seeks a strong and secure future.

## References

- Association of Maternal and Child Health Programs. 1991. Making a difference: A report on Title V maternal and child health services programs' role in reducing infant mortality. Washington: Association of Maternal and Child Health Programs.
- Balla P. 1995. CHIP—a community model for a comprehensive health care system. In: Grason H, Guyer B, editors. Assessing and developing primary care for children: Reforms in health systems. Arlington, VA: National Center for Maternal and Child Health.
- Bell KN, Simkin LS. 1993. Caring prescriptions: Comprehensive health care strategies for young children in poverty. New York: National Center for Children in Poverty.
- Buescher PA, Roth MS, Williams D, Goforth CM. 1991. An evaluation of the impact of maternity care coordination on Medicaid birth outcomes in North Carolina. *American Journal of Public Health* 81(12):1625-9.
- Buescher PA, Larson LG, Nelson MD, Lenihan AJ. 1993. Prenatal WIC participation can reduce low birth weight and newborn medical costs: A cost-benefit analysis of WIC participation in North Carolina. *Journal of the American Dietetic Association* 93(2):163-6.
- Child health in 1990: The U.S. compared to Canada, England and Wales, France, The Netherlands, and Norway. *Pediatrics* 86(suppl):1025-127.
- Combs-Orme T, Guyer B. 1992. America's health care system: The Reagan legacy. *Journal of Sociology and Social Welfare* 19:63-89.
- Elster A, Panzarine S, Holt K, editors. 1993. American Medical Association state-of-the-art conference on adolescent health promotion: Proceedings. Arlington, VA: National Center for Education in Maternal and Child Health.
- Employee Benefits Research Institute. 1996. Sources of health insurance and characteristics of the uninsured: Analysis of the March 1995 current population survey. Issue Brief No. 170. Washington: EBRI.
- Grason H, Guyer B. 1995a. MCH policy research brief: Quality, quality assessment, and quality assurance considerations for maternal and child health populations and practitioners. Baltimore: The Child and Adolescent Health Policy Center, The Johns Hopkins University.
- Grason H, Guyer B. 1995b. Rethinking the organization of children's programs: Lessons from the elderly. *Milbank Quarterly* 73(4):565-97.
- Hayes CD, Lipoff E, Danegger AE. 1995. Compendium of comprehensive, community-based initiatives: A look at costs, benefits, and financing strategies. Washington: The Finance Project.
- Hill I. 1992. The role of Medicaid and other government programs in providing medical care for children and pregnant women. *The Future of Children* 2(2):134-53.
- Hill I, Bennet T. 1990. Enhancing the scope of prenatal services: Strategies for improving state perinatal programs. Washington: National Governors' Association.
- Hill I, Breyel J. 1989. Coordinating prenatal care: Strategies for improving state perinatal programs. Washington: National Governors' Association.
- Hill I, Breyel J. 1991. Caring for kids: Strategies for improving state child health programs. Washington: National Governors' Association.
- Hughes RG, Davis TL, Reynolds RC. 1995. Assuring children's health as the basis for health care reform. *Health Affairs* 14(2):158-67.
- Igra V, Millstein SG. 1993. Current status and approaches to improving preventive services for adolescents. *Journal of the American Medical Association* 269(11):1408-12.
- Jameson EJ, Wehr E. 1993 Fall. Drafting national health care reform legislation to protect the health interests of children. *Stanford Law and Policy Review*: 152-76.
- Kahn AJ, Kamerman SB. 1992. Integrating services integration: An overview of initiatives, issues, and possibilities. New York: National Center for Children in Poverty.
- Kitner J, Page S. 1996. Map and track: Initiatives for young children and families. New York: National Center for Children in Poverty.
- Lesser AJ. 1985. The origin and development of maternal and child health programs in the United States. *American Journal of Public Health* 75: 590-8.

- Lewis-Idema D. 1988. Increasing provider participation: Strategies for improving state perinatal programs. Washington: National Governors' Association.
- McMannus MA, Hertz K. 1995. Private health insurance coverage of preventive benefits for children. In: Solloway MR, Budetti PP, editors. Child health supervision: Analytical studies in financing, delivery, and cost-effectiveness of preventive and health promotion services for infants, children, and adolescents. Arlington, VA: National Center for Education in Maternal and Child Health.
- National Center for Health Statistics. 1988. National health interview survey child health supplement, 1988. Washington: U.S. Government Printing Office.
- National Commission on Children. 1991. Beyond rhetoric: A new American agenda for children and families, summary final report of the National Commission on Children. Washington: National Commission on Children.
- National Research Council. 1993. Losing generations: Adolescents in high risk settings. Washington: National Academy Press.
- Newacheck PW, Hughes DC, Cisternas M. 1995a. Children and health insurance: An overview of recent trends. Health Affairs 14:244-54.
- Newacheck PW, Hughes DC, Brindis C, Halton N. 1995b. Decategorizing health services: Interim findings from the Robert Wood Johnson Foundation's child health initiative. Health Affairs 14(3):232-42.
- Office of Inspector General, Department of Health and Human Services. 1991. Services integration: A twenty-year retrospective. OEL-01-91-00580. Washington: Department of Health and Human Services.
- Omnibus Budget Reconciliation Act of 1989. Public Law No. 101-239, Section 6403.
- Omnibus Budget Reconciliation Act of 1990. Public Law No. 101-508, Section 4601.
- Perloff J. 1992. Health care resources for children and pregnant women. The Future of Children 2(2):78-94.
- Reingold JR, Frank BR. 1993. Targeting youth: The sourcebook for federal policies and programs. Washington: Institute for Educational Leadership.
- Rosenbaum S. 1992. Rationing without justice: Children and the American health system. University of Pennsylvania Law Review 140:1859-80.
- Schroeder SA. 1992. Physician supply and the U.S. medical marketplace. Health Affairs 11(1):235-43.
- Short PF, Bantlin JS. 1995. New estimates of underinsured younger than 65 years. Journal of the American Medical Association 274(16):1302-6.
- Staffeld B. 1991. Primary health care: A cross national comparison. Journal of the American Medical Association 266(16):2268-71.
- U.S. Congress, Office of Technology Assessment. 1991. Adolescent health, Vol. III: Cross-cutting issues in delivery of health related services. OTA-H-467. Washington: U.S. Government Printing Office.
- U.S. General Accounting Office. 1990. Home visiting: A promising early intervention strategy for at-risk families. GAO/HRD-90-83. Washington: GAO.
- U.S. General Accounting Office. 1993. Preventive health care for children: Experience from selected foreign countries. GAO/HRD-93-62. Washington: GAO.
- U.S. General Accounting Office. 1995a. Early childhood programs, multiple programs and overlapping target groups. GAO/HEHS-95-4FS. Washington: GAO.
- U.S. General Accounting Office. 1995b. Health insurance for children: Many remain uninsured despite Medicaid expansion. GAO/HEHS-95-175. Washington: GAO.
- U.S. General Accounting Office. 1996a. Health insurance for children: Private insurance coverage continues to deteriorate. GAO/HEHS-96-129. Washington: GAO.
- U.S. General Accounting Office. 1996b. Health insurance for children: State and private programs create new strategies to insure children. GAO/HEHS-96-35. Washington: GAO.
- Williams BC, Miller CA. 1991. Preventive health care for young children: Findings from a 10-country study and directions for United States policy. Arlington, VA: National Center for Clinical Infant Programs.