

## Chapter 6

### The Care Policy Landscape

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"Care policy" is not a common category in American social policy research, which often organizes social policies simply by the characteristics of recipients. The widely referenced congressional publication *Compilation of the Social Security Laws* (the "Green Book"), for example, categorizes U.S. social policies primarily according to the groups served: the elderly, survivors of deceased workers, people with disabilities, the blind, the unemployed, veterans, mothers, and children. Academic social policy typically disaggregates policies into broad domains such as income support, employment, housing, and health policy (Blau and Abramovitz 2010). In the political arena, public initiatives with budgetary components are often separate from those that do not require direct fiscal outlays. That has the effect of decoupling, for example, child care policies (which generally require public spending) from family leave policies (which often grant leave rights but not wage replacement and thus do not require direct governmental expenditures).

Before we can give care policy the sustained and systematic attention that it deserves, we must develop a clear definition of its content and boundaries. As several contributors to this volume have argued, defining "care" presents an ongoing conceptual challenge; the same is true, of course, with respect to "care policy." Identifying and assessing care policies is especially challenging in the United States because of the complex, often overlapping divisions of labor between national and state governments. In many aspects of care policy, both federal and state levels of government are key actors in revenue generation, spending, and direct provision of care, as well as in various aspects of rule setting and regulation, from determining eligibility to quality assurance.

We begin this chapter by defining the universe and boundaries of care policy, limiting ourselves to policies that directly shape the provision or receipt of care for children or for adults who need personal assistance. The next section provides an overview of early childhood education and care policy, family leave policy, foster care policy, and

services and special education for children with disabilities. The third section provides a parallel description of care for adults, focused on long-term care services and supports. For each of the policy categories, we clarify, in general terms, the nature of the policy, its intended purpose, the size of the population potentially and actually served, and its key components at both the national and state levels. We close each policy section with a discussion of current estimated national and state expenditure levels. We conclude the chapter with some remarks about the care policy landscape as a whole.

#### DEFINING CARE POLICY

A large system of policies, regulations, and institutions indirectly affects the nature and adequacy of care provided in the United States. This system includes an array of income transfers and tax expenditures (such as Social Security and the Earned Income Tax Credit [EITC]); near-cash and non-cash supports (such as food stamps, subsidized school lunches, and housing assistance); regulations that shape working conditions (such as minimum wages and overtime thresholds); public education (including investments in primary, secondary, and tertiary education); and institutions of social control (including the juvenile and adult criminal justice systems).

These government policies and institutions transfer crucial goods and services and shape the private acquisition of resources in ways that affect individuals' and families' access to care and to resources to be used for care. Under this wide umbrella are a number of policies that more *directly* shape care provision and receipt for children and adults needing personal assistance. We divide these two overarching categories of care recipients—children and adults—into seven subcategories and map them onto the main care policies that typically or potentially serve them and their caregivers, as shown in table 6.1. Our research suggests that the policies listed there are the largest and most substantial public initiatives related to the direct provision of care, as measured by the number of care recipients (or potential recipients), the level of expenditures, or both. Included are policies that operate through a diversity of mechanisms, such as direct provision, demand- or supply-side subsidies, and employment regulation. Also included are diverse governmental structures, from purely national programs to federal-state matching programs, federally funded block grants, state programs that extend eligibility for or benefits from national programs, and autonomous state programs.

The first two groups served are children in the early developmental stages who live with their families (a small subset of whom have disabilities). Children are often cared for in programs that supplement or substitute for parental child care or provide early educational opportunities on a daily basis. For the children of employed parents, crucial support is also granted through public family leave policies. These policies grant rights—and in some cases cash benefits—that enable parents to take temporary breaks from employment to care for their own children. They sometimes also cover care for other family members.

The third group is made up of children whose parents or guardians cannot care for them at home. These children are often cared for in the foster care system, sometimes being placed with extended kin but frequently with entirely new families.

TABLE 6.1 / Care Recipients and Care Policies

Groups That Need or Benefit from Care Policies	Policy Components				
	Early Childhood Education and Care (ECEC)	Family Leave <sup>a</sup>	Foster Care	Early Intervention and Special Education	Long-Term Services and Supports
<b>Children</b>					
Children with primary parent or caregiver who is not employed	X				
Children with primary parent or caregiver who is employed	X	X			
Children who need residential care <sup>b</sup>	x	x	X		
Children with disabilities	x	x	X	X	X
<b>Adults</b>					
Adults with intellectual and developmental disabilities (ID/DD) <sup>c</sup>		x	X		X
Adults with disabilities other than ID/DD		x	X		X
Frail elderly adults		x	X		X

Source: Authors' summary.

Notes: A large "X" signifies the policy arena(s) most central to providing care to this group or support for their caregivers. A small "x" denotes policies that affect access to and receipt of care but are arguably less crucial to responding to the need for care.

<sup>a</sup>Leaves granted to employees to care for infants or seriously ill family members.

<sup>b</sup>Because their parents are judged unable to care for them at home.

<sup>c</sup>Disabilities that have manifested at birth or prior to age twenty-two and are expected to continue indefinitely.

(There is also overlap between this group and the first two, since foster parents may place their foster children in early childhood education and care [ECEC] programs or draw on family leave options.)

The fourth group is children with disabilities. They receive an array of services and supports, including special education, whose goal is to help them achieve maximum possible social integration in adulthood. Some also receive long-term services and supports.

The three groups of adult recipients include individuals with a diverse range of physical and mental conditions that limit their capacity for social integration, work, or self-care. They are served by institutional and home- and community-based long-

term care and support services that assist them with basic activities and help them live safely. Ideally, these services also maximize care recipients' independence and foster their integration into the community. These adults may also receive support in the form of short-term family leaves granted to their employed family caregivers if their caregivers need to take time off from work to help them during a temporary but serious illness.

## POLICIES THAT SUPPORT THE CARE OF CHILDREN

Public policies that support children and their caregivers are directed at one of four areas: early childhood education and care, family leave, foster care, and disability services and supports.

### Early Childhood Education and Care

Early childhood education and care is an essential form of support for families with children, especially those with children below primary school age.<sup>1</sup> We use the term "early childhood education and care" to encompass two types of programs: child care programs that are primarily intended to provide substitutes for parental care, and early education programs, such as Head Start and prekindergarten programs, that have an explicit educational purpose.

ECEC policies are crucial for children without a stay-at-home parent: they allow parents to commit to working outside the home secure in the knowledge that they can find reliable care for their children. But children whose primary caregivers do not work for pay also benefit from publicly supported ECEC programs, especially those with an educational focus.

**RECIPIENTS AND POTENTIAL RECIPIENTS** While most nonparental care in the United States is arranged, provided, and financed privately, a substantial minority of the children who receive early childhood education and care are in programs that get most or all of their financing from public funds. In 2006 about 2.5 million children received care financed by the major means-tested assistance programs described here, while another 1.9 million were enrolled in state- or federally funded early education programs. In addition, 4.4 million families claimed some of their out-of-pocket expenditures, although an unknown (but most likely relatively small) number of these claims supported the care of adult dependents rather than children. An additional unknown number also benefited from tax benefits for dependent care through employer-provided Dependent Care Assistance Programs (DCAPs) (McKenna 2010).

According to the U.S. Census Bureau's *Who's Minding the Kids* report, in 2010, of the 8.7 million families with children under age five and mothers who were employed, nearly half (4.0 million) made payments for ECEC services. Of all children under age five with working mothers, nearly half were primarily cared for in institutional settings or by non-relatives, types of ECEC that typically require either

public funding or private payment (U.S. Census Bureau 2011a). Another 12.6 million families with working mothers had children older than five but younger than fifteen. Nearly one-quarter (2.8 million) of these families used paid ECEC services (U.S. Census Bureau 2008c). The 21.2 million families with working mothers and children under age fifteen represented about two-thirds of the roughly 34 million U.S. families with children (U.S. Census Bureau 2011b). In the context of the utilization levels reported here for publicly-funded ECEC programs, this suggests that a substantial minority of families with children receive some type of publicly funded, non-parental ECEC.

**THE POLICY LANDSCAPE** In this chapter, our focus is the publicly funded care provided to the substantial minority that received public support. As summarized in table 6.2, ECEC policy in the United States has four core components: (1) public early education policies, (2) means-tested programs that provide child care assistance, (3) tax benefits for parents, and (4) regulation of quality.

**PUBLIC EARLY EDUCATION PROGRAMS** Although some early education programs, such as prekindergarten, serve children regardless of income, others are designed to enhance the social and intellectual development of low-income children and to reduce disparities in school-readiness between more and less affluent children. The single largest compensatory early education effort is the federal Head Start program, which provides part-day educational services funded through federal grants to state and local providers. About three-quarters of the states provide additional funding for Head Start or operate parallel state programs. Head Start provides high-quality, developmentally oriented education (and health) services to children. It also offers educational, social, and mental health services to their parents. Recent federal initiatives have extended Head Start services in some locations both downward (to serve younger children) and outward (to provide full-day services).

In recent years, states have also taken the lead in expanding early education programs. These programs are designed to increase the school-readiness of all children, with particular benefits for children with impoverished home environments or other forms of disadvantage. (In our later discussion of programs for children with disabilities, we describe programs with similar goals targeted to children with disabilities.) Well over half (thirty-eight) states currently operate state-funded prekindergarten programs. In 2008–2009, more than 1.5 million three- and four-year-olds were served by these programs—more than double the number served by Head Start programs (Barnett et al. 2009). In addition, all states provide kindergarten, which is attended by nearly all the nation’s five-year-olds. However, there is evidence that state-funded prekindergarten programs may be facing substantial cuts in many states over the next several years as a result of the recession, leaving their future uncertain (Epstein and Barnett 2010).

**MEANS-TESTED ASSISTANCE** Means-tested assistance is designed to reduce the cost of substitute care for low-income employed parents, either by subsidizing child care provision (supply subsidies) or by increasing the purchasing power of low-income families in the private child care market (demand subsidies). Means-tested

TABLE 6.2 / Early Childhood Education and Care Policies

	Early Education	Means-Tested Child Care Assistance	Tax Benefits	Quality Regulation
Federal-state	Head Start: Provides means-tested compensatory education for children primarily ages three and four	Child Care and Development Fund (CCDF): Provides means-tested subsidies for employed parents with children up to age thirteen Temporary Assistance to Needy Families (TANF): Provides means-tested subsidies for employed parents receiving or transitioning from public assistance Social Services Block Grant (SSBG): Provides means-tested subsidies for employed parents	Child and Dependent Care Tax Credit (CDCTC): Nonrefundable tax credit for out-of-pocket expenses  Dependent Care Assistance Program (DCAP): Provides employer-sponsored “flexible spending accounts” exempting out-of-pocket expenses from payroll and income taxes	
State-local	Prekindergarten and kindergarten programs provide universal or targeted educationally oriented care to children ages three to five		State-based tax credits provide tax relief for out-of-pocket expenses	Licensing and regulatory mechanisms establish and enforce health, safety, and quality standards

Source: Authors’ summary.

child care assistance has grown sharply in recent years as an element of welfare reform policies designed to require and support employment among welfare recipients (Meyers et al. 2011).

Since 1996, the federal government has provided the bulk of funding for means-tested child care assistance, through three block grants to the states. The single largest source of federal funding for means-tested subsidies is the Child Care and Development Fund (CCDF), a federal block grant to the states. States may use CCDF funds to provide child care assistance to working families with incomes up to 85 percent of the state median, although many choose to set the threshold lower. Federal guidelines require states to offer parents a choice of care types and providers, but states are free to set other CCDF policies, including standards for eligibility, levels of parental copayment, and provider reimbursement.

The second major funding stream for means-tested assistance is the Temporary Assistance for Needy Families (TANF) block grant, which replaced the Aid to Families with Dependent Children (AFDC) program in 1996. States are authorized to transfer up to 30 percent of their TANF funds to the CCDF program, and virtually all states transfer some of their TANF resources to child care expenditures. In some states, dedicated CCDF spending makes up almost 100 percent of state child care spending, while in others the majority is funded by TANF dollars allocated to child care (Meyers et al. 2011). States also use TANF funds directly to provide child care (largely through vouchers) for welfare-reliant families who are preparing for work and for current and former welfare recipients who are employed.

The Social Services Block Grant (SSBG) provides the third and smallest source of federal child care assistance for poor families. The SSBG provides federal funds for a wide range of services to the poor, and states have almost complete discretion in deciding how to allocate them, including whether to spend any on child care. As of 2007, an estimated 13 percent of all SSBG funds were used for child care services or vouchers (U.S. Department of Health and Human Services/OCS 2007).

**TAX BENEFITS** Tax deductions and credits constitute the third-largest form of assistance. The federal Child and Dependent Care Tax Credit (CDCTC) allows parents to deduct 20 to 35 percent of their out-of-pocket expenses from their taxable earnings. Lower-earning parents deduct higher percentages, but because the federal CDCTC is a nonrefundable tax credit, it does not benefit families whose incomes are too low for them to pay income tax. Benefits under the federal tax credit are capped and decline in value for higher-income families, ranging from \$600 to \$1,050 for one child and from \$1,200 to \$2,100 for two or more. The lowest-income families (below \$15,000 per year in adjusted gross income) can deduct 35 percent of child care expenses up to \$3,000 for one child or \$6,000 for two or more children—the percentage of expenses that can be deducted decreases incrementally, down to 20 percent for families making \$43,000 or more annually (Internal Revenue Service 2009).

Families working for participating employers may elect to use a Dependent Care Assistance Program (DCAP) instead of the CDCTC to deduct their care expenses by diverting a portion of their salary into a tax-free account that can be used to pay

for services. DCAP functions like a tax deduction, allowing families to deduct up to \$5,000 in care expenses from their taxable income; the program may yield somewhat higher benefits than CDCTC for some families, depending on how many children they have and their income tax bracket. As with CDCTC, DCAP primarily benefits higher-income families who owe taxes, but the benefits are even greater for the highest-income families, as the net benefit of the program depends on the tax bracket of the participating family. DCAP deductions also benefit employers, who save their portion of payroll tax on the funds that their employees divert into the account. Despite this fact, DCAP is offered to only about one-third of all private-sector workers. Workers with higher income, those in certain industries, those in the public sector, and those in large firms are much more likely to work for employers that offer DCAP, while those who earn too little to owe income taxes are unlikely to have access to the program, nor would they gain any benefit from it (McKenna 2010).

Tax credits for care such as CDCTC and DCAP can provide substantial benefit to middle-income and higher-income families—these credits are potentially worth marginally more than the subsidies available to low-income families through CCDF. However, typically CCDF beneficiaries who do collect subsidies collect more through these programs than those with higher incomes who claim tax subsidies. In the final tally, what is most notable is that programs that provide support for child care are available across the income spectrum, at roughly equivalent (low) levels of subsidy—as such, they are broad-based, relatively flat in their redistributive impact by income, and, unfortunately, inadequate to cover the costs of quality child care (McKenna 2010).

In addition to the federal tax benefits outlined earlier, over half of all states now provide additional child care tax credits. Many are based in part on the federal credit (the CDCTC), but some diverge from the federal structure to target low-income families more directly, either by enacting refundable tax credits (which can be used even by families with income too low to owe income tax) or by limiting the credits to families at lower income levels (Maag 2005).

**QUALITY REGULATION** The effects of substitute care on children's safety, health, and intellectual and emotional development depend largely on the quality of care received. Quality is a product of several factors: basic health and safety characteristics (such as the cleanliness and safety of the setting), structural factors (such as the number of children cared for and the number of adults providing supervision), and characteristics of the providers (especially education and training, job experience, and level of investment or engagement in their work, all of which may have an impact on the type and quality of their interactions with children).

In the highly privatized U.S. system, the government provides largely post hoc control over the quality of care, through licensing requirements and enforcement. The licensing of ECEC services is left to state governments; outside of the federal Head Start program, there are no national standards for staffing, health and safety, or teaching curricula. State licensing requirements, standards, and rigor vary enormously from state to state. Many states exempt some forms of care from regulation (for example, small family day care homes or centers in religious institutions). For

those they do not exempt, all states regulate basic health and safety standards and set maximums for group size and for numbers of children per adult provider. Few go beyond these basics, however, to address other issues such as provider education and training standards.

**TOTAL ECEC EXPENDITURES** Public expenditures on child care via CCDF, TANF, and SSBG totaled \$13.6 billion in 2006, the most recent year for which figures are available. CCDF spending accounted for \$9.2 billion of that total, TANF funds allocated to child care totaled \$4.3 billion (Meyers et al. 2011), and SSBG allocations were just under \$100 million (net of TANF transfer) (U.S. Department of Health and Human Services/ACF/OCS 2008). In addition, nonrefundable tax credits granted through the federal CDCTC totaled \$3.2 billion, and benefits provided via DCAPs amounted to \$600 million (Maag 2007). Twenty-seven states contributed additional subsidies in the form of state-level tax dependent care credits, but total state-level expenditures for child care-related tax benefits are not available (National Women's Law Center 2006).

Public expenditures on early education are also substantial, amounting to nearly \$10 billion in 2006. Of that total, federal and state expenditures on Head Start amounted to \$5.8 billion and \$123 million, respectively. State and federal expenditures on public prekindergarten programs added up to \$3.6 billion and \$154 million, respectively (Meyers et al. 2011). Although these programs do serve a large number of children at a significant cost, they are dwarfed by the cost of primary and secondary education in the United States—in the 2005–2006 school year, total spending on public elementary and secondary education totaled \$528 billion (U.S. Department of Education/NCES 2011).

## Family Leave

Family leave policy refers to a set of publicly secured rights and benefits that allow employees to take time off from paid work to temporarily care for family members. Family leaves, which exist at both federal and state levels and may be paid or unpaid, are typically granted to parents to care for infants (either born to the family or newly adopted) or to care for seriously ill family members. In addition to family leave laws, some public provisions grant medical leave, allowing workers to take time off when they themselves are incapacitated or ill. Because this volume focuses mainly on care for people other than oneself, we focus our attention here on family leave.

Family leave policies have diverse and overlapping goals: to provide new parents with time for recovery and bonding, to secure care for those in need, to increase and strengthen women's employment, to prevent employee turnover or raise labor force productivity, to protect families from economic insecurity during periods of caregiving, and, in some cases, to encourage men and women to share caregiving work more equally.

As with ECEC, in the United States family leave provisions are mainly provided through the market, with relatively limited public intervention. ECEC is primar-

TABLE 6.3 / Family Leave Policies

	Leaves for Mothers Due to Pregnancy or to Care for Infants	Leaves for Mothers and Fathers to Care for Infants	Leaves to Care for Ill Family Members
Federal	Pregnancy Discrimination Act (PDA): Requires that providers of disability benefits (employers, states) cover maternity	Family and Medical Leave Act (FMLA): Grants mothers and fathers the right to unpaid leave during first year of child's life	Family and Medical Leave Act (FMLA): Grants the right to unpaid leave to attend to serious illness of child, spouse, or parent
State	Temporary Disability Insurance (TDI): Provides limited paid maternity leaves to pregnant or new mothers (in California, Hawaii, New Jersey, New York, and Rhode Island only)	Various laws expand unpaid FMLA, mainly by reducing the minimum enterprise size threshold, increasing the benefit duration, extending the definition of family members (who can be cared for), and relaxing eligibility conditions. California and New Jersey provide paid leaves for infant and relative care. Washington passed a law providing paid infant care leaves, but it remains unfunded.	

Source: Authors' summary.

ily provided via consumer markets, while family leave rights and benefits—particularly the full or partial wage replacement that is granted to some employees while on leave—are, to a significant extent, left to the labor market.

The public component of family leave provisions summarized in table 6.3 has three core elements: leaves granted to birth mothers due to pregnancy or to care for infants (usually referred to as “maternity leave”), leaves granted to mothers and fathers to care for infants (often called “parental leave” or “bonding leave”), and leaves granted to care for seriously ill family members (“caring leave”). On the federal level, public family leave benefits pertain only to employees' right to take *unpaid* time off from work. Currently there are two states that provide *paid* parental and caring leaves; these two states, California and New Jersey, and three additional ones—Hawaii, New York, and Rhode Island—provide paid maternity leave benefits through state temporary disability insurance (TDI) programs.

**RECIPIENTS AND POTENTIAL RECIPIENTS** Family leave rights and benefits affect an enormous number of Americans. Although it is difficult to estimate the number of workers who need or take family leave in a given year, some information is available related to the Family and Medical Leave Act (FMLA), the national law that grants unpaid leaves to qualified employees. Information is also available about the numbers served in the two states that have paid family leave programs up and running, California and New Jersey. Hawaii, New York, and Rhode Island also provide paid maternity leave as part of their state TDI programs, but it is

impossible to distinguish maternity leaves from the larger universe of medical leaves that workers take to care for themselves. The FMLA and state paid family leave programs are described in detail later in this chapter.

Regarding unpaid leave, a 2007 Department of Labor study found that 76 million workers (about half of the U.S. workforce) were eligible to take unpaid leaves in 2005 under the provisions of the FMLA. Of those 76 million workers, between 6 million and 13 million took qualified leaves during 2005 (U.S. Department of Labor 2007). An earlier report (U.S. Department of Labor 2000) found that slightly over half of FMLA leaves are taken due to pregnancy or the need to care for family members, including caring for a new child or recovering from a maternity disability (26 percent), caring for a seriously ill parent (13 percent), caring for a seriously ill child (12 percent), or caring for a seriously ill spouse (6 percent). Medical leaves, taken due to an employee's own serious illness, constitute the other half of FMLA leaves. (As noted earlier, we largely omit consideration of medical leave in this volume.)

With respect to paid leave, the flagship paid-leave states—California and New Jersey—grant some wage replacement to substantial numbers of workers and their families. In California in 2009–2010, paid family leave benefits were granted to 181,000 women and men; in addition, California's TDI program paid pregnancy- or childbirth-related claims to about 170,000 women (State of California/EDD 2010b). Also in 2009–2010, the nation's newest paid family leave program, in New Jersey, awarded benefits to 28,000 men and women; in addition, New Jersey's TDI program granted pregnancy- or childbirth-related benefits to nearly 26,000 women (State of New Jersey/DOLWD 2010c). It is important to note that in both states, women may be eligible for both paid family leave and pregnancy-childbirth benefits under state TDI programs. Unfortunately, data that provide unduplicated counts of beneficiaries across these two programs are not available.

**THE POLICY LANDSCAPE—UNPAID LEAVE** Rights to unpaid family leaves were established nationally in 1993 with the passage of the Family and Medical Leave Act (FMLA), the first piece of legislation signed by President Clinton and the culmination of an eight-year political battle. The FMLA applies to all public employers and to private employers with fifty or more employees—which includes only 4 percent of firms but more than 70 percent of workers (U.S. Small Business Administration 2010). Within the establishments it covers, eligibility is extended only to workers who have been employed for at least twelve months and have worked a minimum of 1,250 hours in the prior year. The law does not address wage replacement, although it requires employers to continue contributions to workers' health insurance during covered leaves.

Employees who meet FMLA eligibility standards have the right to up to twelve weeks of unpaid, job-protected leave to care for a child after birth or following placement for adoption or foster care. The FMLA also provides eligible workers up to twelve weeks a year to care for seriously ill family members—including sons, daughters, spouses, and parents. Nearly one-third of FMLA leaves are taken to care for family members other than infants (U.S. Department of Labor 2000).<sup>2</sup> The FMLA defines a son or daughter as a "biological, adopted, or foster child, a stepchild, a legal ward,

or a child of a person standing in loco parentis" (U.S. Department of Labor 2010). It defines serious illness as a medical condition requiring hospitalization or continuing treatment by a health care provider. The FMLA allows workers to take these leaves in "chunks" when necessary—a few hours, a day, or a week at a time.

Several U.S. states supplement the FMLA with laws that expand the pool of workers who are eligible or increase the maximum time granted per leave. A variety of state provisions have been implemented that expand FMLA eligibility to more workers or more circumstances. Some states require private employers with fewer than fifty workers to provide leaves, some relax worker eligibility conditions related to tenure or hours worked, and some extend the range of family members who may be cared for (including, for example, grandparents, grandchildren, and in-laws). Several states have also increased the duration of job-protected leave benefits to grant more than twelve weeks of leave per year.

**THE POLICY LANDSCAPE—PAID LEAVE** Two government mechanisms shape American mothers' access to paid maternity leave, both operating within the framework of disability policy. One is the national Pregnancy Discrimination Act (PDA) of 1978, an amendment to Title VII of the 1964 Civil Rights Act. The PDA mandates that public and private employers that offer disability benefits must extend them to employees for pregnancy, childbirth, and pregnancy-related medical conditions. Importantly, while the PDA mandates that employers that provide disability benefits must include maternity, it does not require employers to offer disability benefits.

In addition, five U.S. states—California, Hawaii, New Jersey, New York, and Rhode Island—provide paid maternity leaves to insured workers. These leaves are paid through state TDI programs,<sup>3</sup> which provide some wage replacement in the event of short-term disability—and thanks to the PDA, short-term disability must cover pregnancy and a postbirth period for new mothers. Weekly TDI benefits range from about \$170 to \$959, and the average duration of a claim is six to eight weeks (Fass 2009).

Three states have enacted paid family leave programs that serve both men and women. Two of the three are TDI states (California and New Jersey), and the third is Washington. California became the first state to extend what it calls paid "bonding leave" to fathers (in addition to mothers), in a 2002 law that grants six weeks of paid infant-care leave to parents of both genders, in addition to the TDI-covered maternity period granted to mothers. Benefits are set at approximately 55 percent of wages up to a maximum level of earnings. Washington's 2007 law will provide five-week leaves for both mothers and fathers, but it has yet to be funded. New Jersey's 2008 law provides for up to six weeks of paid leave in addition to TDI-based maternity benefits. The California and New Jersey laws also grant paid leaves to care for other family members during periods of serious illness, while Washington covers infant care only (Economic Opportunity Institute 2007).

**EXPENDITURES** There are no estimates of total expenditures on maternity leave as distinct from other medical and disability leaves across the five TDI states. However,

some expenditure data are available for both California and New Jersey. Those data include spending on these states' new paid family leave programs, as well as on pregnancy- and childbirth-related leaves in their long-standing TDI programs.

California operates the largest paid family leave program in the United States. The state spent \$469 million on paid family leave benefits in 2009–2010. California also spent \$4.4 billion on its TDI program overall, with maternity claims totaling \$708 million (16 percent) of that total. Pregnant women and new mothers in California took an average of 10.5 weeks of leave, collecting an average benefit of \$397 per week (State of California/EDD 2010b).

New Jersey spent \$35 million on paid family leave benefits, from July 2009 through July 2010. During calendar year 2009, New Jersey also spent \$437.4 million on its TDI program, with 25 percent of claims being paid to women for time taken off from work during pregnancy or after childbirth. Unlike in California's temporary disability program, the average weekly benefit for TDI maternity claims in New Jersey was virtually identical to the overall average weekly benefit in the program—about ten weeks. Assuming that the average weekly benefit for TDI maternity claimants and overall TDI claimants have the same relationship to each other in New Jersey as in California, then TDI maternity claims in New Jersey totaled roughly \$92 million in 2009 (State of New Jersey/DOLWD 2010).

## Foster Care

In foster care—also referred to as “out-of-home care”—minor children whose parents or guardians are unable to ensure their well-being, either temporarily or permanently, are placed in the homes of adults other than their parents or guardians or in institutional settings. Parents or guardians sometimes place children in foster care voluntarily. In other cases, children who have been found to face the risk or actual occurrence of physical or psychological harm at home are placed in foster care by the state without the participation of the parent or guardian.

Foster care may be short-term or long-term; in either case, it is intended to be temporary. The goal of the child welfare system is to find a safe and stable permanent home for children by either returning them to their original home, if possible, or placing them permanently with another family. A primary purpose of foster care, as part of the child welfare system, is to develop and achieve a plan for permanent placement. Foster care allows for a range of outcomes, from family reunification to adoption to emancipation, which happens when a foster child reaches the age at which they become legally independent.<sup>4</sup>

**RECIPIENTS AND POTENTIAL RECIPIENTS** Nearly half a million children—an estimated 463,000—were in the foster care system in the United States in September 2008. As mentioned in chapter 1, this represents roughly one-half of 1 percent of all children under age eighteen nationwide. Seventy-one percent of children in foster care are placed with foster families, with the bulk of these placed in nonrelative homes (47 percent) and the remainder with relatives other than their parents or guardians (24 percent). Sixteen percent are placed in group homes or

institutional care, with the remainder placed in preadoptive (4 percent) or trial homes (5 percent); a small share (2 percent) are unaccounted for—runaways, for example (U.S. Department of Health and Human Services/ACF/ACYF/CB 2008).

In addition, many children are in ad hoc out-of-home care arrangements that are not mediated by the foster care system, as when a relative or family friend takes in a child informally when the parents are unable to care for the child. According to findings from the National Survey of America's Families (NSAF), only 10 percent of children living with relatives other than their parents are in formal kinship foster care arrangements; over 2 million children have been placed in informal kin care or voluntary kinship care (where kin care arrangements are mediated by child welfare agencies but children are not in the custody of the state) rather than foster placements with family members per se (Urban Institute 2003; Geen 2004). Children in these informal kin care arrangements do not receive the services or financial support that would accrue to children in official foster care.

**THE POLICY LANDSCAPE** The U.S. foster care policy system, as summarized in table 6.4, includes four main components: federal and state child welfare regulations; federal, state, and local foster care and adoption regulations; dedicated federal and state funding for foster care and adoption services; and federal block grant funding.

**FEDERAL POLICIES** The primary responsibility for foster care—and for child welfare in general—has traditionally rested with state and local government agencies and, to some extent, with nonprofit child welfare organizations and foundations, which provide services both independently and as contractors to and collaborators with government agencies. However, the role of the federal government in the child welfare system has grown as the federal government has increased its targeted funding to states. This funding is tied to new requirements emphasizing greater state accountability in achieving positive outcomes for children. Several major pieces of federal legislation—including the Child Abuse Prevention and Treatment Act (CAPTA) and the Keeping Children and Families Safe Act (KCFSA)—have played a significant role in structuring the modern child welfare system, through a combination of financing provided to states and regulatory policy.

Federal funds, from more than thirty different programs, account for roughly half of states' total reported spending on child welfare services. The major federal funding source for foster care services, established in 1980, is the Title IV-E program (Federal Payments for Foster Care and Adoption Assistance); this funding stream shares the cost of foster care services with the states. The 1997 Adoption and Safe Families Act (ASFA) amended Title IV-E, shifting the emphasis to increasing the number of adoptions and encouraging states to emphasize permanency planning. Additional federal financing for foster care services comes through the Social Services Block Grants (SSBG) and Temporary Assistance for Needy Families (TANF) funding streams, which, as in the case of means-tested child care benefits, states may direct toward their foster care programs (Murray 2004).

Additional support to increase incentives for adoption among low-income families is provided through the Adoption Tax Credit, which became a permanent part of the

TABLE 6.4 / Foster Care Policies

	Regulatory Policy		Funding Streams	
	Child Welfare Policy Framework	Specific Foster Care and Adoption Regulatory Policies	Dedicated Foster Care and Adoption Funding	Nondedicated Funding Streams Used for Foster Care and Adoption
Federal-state	Child Abuse Prevention and Treatment Act (CAPTA) and Keeping Children and Families Safe Act (KCFSA): Help states improve practices in preventing and treating child abuse and neglect	Adoption and Safe Families Act (ASFA): Aims to accelerate permanent placements for children in foster care	Title IV-E (Federal Payments for Foster Care and Adoption Assistance): Provides funds to the states to cover a share of the cost of foster care Adoption Incentive Payments (established in ASFA) and the Adoption Tax Credit: Provide financial support to adoptive families	Social Services Block Grant (SSBG) Temporary Assistance for Needy Families (TANF): Provides additional funding for foster care
State-local	State and local agencies regulate and administer a wide array of child welfare programs.			

Source: Authors' summary.

tax code in 2001. In 2010, following expansion of the credit as part of the Health Care and Education Reconciliation Act (HCERA), adoptive families may claim refundable tax credits of more than \$13,000 per eligible child, as long as family income does not exceed the average \$22,000 phase-out cap (Internal Revenue Service 2009; Commission for Children at Risk 2010).

**STATE AND LOCAL POLICIES** Beyond these national regulatory guidelines and funding structures, all other details of foster care policy are the responsibility of states and local agencies. States vary markedly with respect to the standards

and procedures by which children are removed from their families, placed in foster care, and transitioned out of the system; the requirements imposed on foster parents and facilities and their remuneration; the procedures for determining permanency goals; family unification and visitation policies and rights; the training, support services, and other resources provided to families working toward reunification; and the legal processes governing adoption, which present a complex set of policy issues. In spite of this significant variation between states, some of the central policy issues have been addressed in the Interstate Compact on the Placement of Children, an agreement among the states regarding best practices for the placement of children and the sustainability of adoptive families.

**EXPENDITURES** In 2006 estimated total spending on foster care, both federal and state, was \$10 billion, of which approximately 40 percent (\$4 billion) came from federal Title IV-E funds. Of that \$4 billion in Title IV-E funding, about 43 percent was spent on payments to foster care providers (known as maintenance payments); the remainder was allocated to administration, child placement services, training, and child welfare information systems (Child Trends 2010). Unfortunately, similar data detailing the distribution of the state portion of foster care spending are unavailable.

### Services for Children with Disabilities

Children with chronic illnesses or physical, mental, intellectual, or developmental disabilities or delays need a range of special medical, therapeutic, educational, and personal assistance services. A small number of children receive the long-term care services discussed in the next section on adults, but most of these children live in their own homes and are cared for by their parents. They receive services until the age of eighteen and twenty-two through two programs specifically targeted to children—Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), which is a mandatory Medicaid benefit for low-income children, and programs under parts B and C of the Individuals with Disabilities Education Act (IDEA), a non-means-tested program that provides early intervention services for children from birth to age three and special education from age three to age twenty-two.

Both programs use a much broader definition of disability than that for adult programs. For children, the definition is based on a developmental model, which is meant to identify not just children who already have disabilities but also those at risk of developing chronic conditions or limitations if they do not receive medical treatment and educational remediation. Most children with disabilities enrolled in EPSDT and special education programs are not considered disabled by the time they reach adulthood. Those who continue to meet a Social Security Act definition of disabled for adults become eligible for the adult programs discussed later in this chapter (Institute of Medicine 2007).

Many states have also adopted Medicaid waiver programs—so-called because the state is allowed to waive some Medicaid rules, including with respect to income eligibility—which have expanded eligibility for children with disabilities. Many



states and localities provide additional support services for the families of children with disabilities, and localities manage and partially finance special education programs through their school systems. Policies for children with disabilities are summarized in table 6.5.

**RECIPIENTS AND POTENTIAL RECIPIENTS** In 2008 there were 74 million children below the age of nineteen in the United States, of whom roughly 4 million had a disability in the form of an activity-limiting health care need. That number included 3.5 million school-age children and another 500,000 under the age of six, about half in families whose incomes fell below 200 percent of the poverty level.<sup>5</sup> Two million children with disabilities were insured by the means-tested, Medicaid-financed EPSDT programs or by Children's Health Insurance Programs (CHIP), according to the 2007 National Survey of Children's Health (NSCH). Most low-income children with special health care needs get comprehensive health care services, including long-term medical and therapeutic treatments, personal assistance, or even institutional services, through EPSDT (Rosenbaum, Wilensky, and Allen 2008).

Estimates extrapolated from the 1994–1995 National Health Interview Survey on Disability reveal that approximately 1 million children age five and younger and another 1.5 million school-age children had intellectual and developmental disabilities (Larson et al. 2000).<sup>6</sup> Many low-income children with ID/DD are covered by EPSDT. Some whose families earn too much to qualify receive services through Medicaid waivers. In addition, twenty states had Medicaid waiver programs designed for medically fragile or technology-dependent children. Just over 20,000 children were enrolled in those programs in 2006, but almost as many—19,000—were on waiting lists (Harrington, Ng, and Watts 2009).

Despite the many services available through Medicaid for children with disabilities, only about 15 percent of low-income children with disabilities and chronic care needs enter Medicaid through disability services (Rosenbaum, Wilensky, and Allen 2008). Medicaid's programs for people with disabilities, which are discussed later in more detail in the section on adults with disabilities, become important mainly when children age out of EPSDT at the age of twenty-one or nineteen.

Because early intervention and special education are not means-tested, public special education services are available to most children with ID/DD. Of the 1.5 million school-age children with ID/DD, an estimated 1.36 million received special education services (Larson et al. 2000). Overall, 6.6 million children age three through twenty-one received special education services, and another 280,000 children under age three were enrolled in early intervention services through the Individuals with Disabilities and Education Act in 2008 (U.S. Department of Education/NCES/IES 2009).

**HEALTH CARE (EPSDT AND CHIP)** Because of its broad range of services and flexible eligibility criteria, EPSDT is the primary source of acute and preventive medical care and long-term support for disabled children (Rosenbaum, Wilensky, and Allen 2008; Johnson 2010).<sup>7</sup> All children age five and younger living in families whose incomes fall below 133 percent of the federal poverty level are eligible

TABLE 6.5 / Children with Disabilities Policy Schematic

	Comprehensive Health Care	Long-Term Services and Supports	Early Intervention and Special Education
Federal-state	Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT): Requires that the states provide comprehensive means-tested health care for children under the age of twenty-two, including screening, diagnosis, and treatment	Medicaid long-term care provisions: Require that the states provide means-tested institutional care	Individuals with Disabilities Education Act (IDEA)—Part B: Provides special education for children age three to twenty-one
State-local		Medicaid means-tested waivers and state plan personal care services option: Finance and deliver means-tested non-institutional care and family support services	Individuals with Disabilities Education Act (IDEA)—Part C: Provides in-home early intervention services for children below age three who show signs of developmental delay
		Some states provide additional family support services.	States and localities provide and fund special education programs.

Source: Authors' summary.

for comprehensive health care insurance under EPSDT. After age five, the federally mandated income eligibility requirement drops to 100 percent of the poverty level. However, states have the authority to expand Medicaid eligibility beyond these minimum standards—up to a maximum of 300 percent of the federal poverty level. Most states also have insurance programs for children whose incomes exceed the maximum allowable level for EPSDT eligibility. These programs are funded under the joint federal-state Children's Health Insurance Program; created in 1997, CHIP covers about 6 million children (Kaiser Family Foundation 2010).<sup>8</sup> Children enrolled in EPSDT are entitled to any service covered in the state's Medicaid plan.<sup>9</sup> Treatment under EPSDT may include a range of long-term services and supports, including personal care services (Rosenbaum 2008).

**OTHER MEDICAID LONG-TERM SERVICES AND SUPPORTS** In most states, children qualify for Medicaid long-term supports and services if they have a disability or chronic illness and have qualified for Supplemental Security Income (SSI). Eligibility for SSI depends on the child's household satisfying a means test (Social Security Administration 2011).<sup>10</sup> The cost of institutional care or equivalent services in the home can have catastrophic financial implications for families whose incomes exceed the Medicaid threshold for eligibility. Prior to 1982, parents' income and assets were deemed part of their children's income and assets only if the children lived at home. Qualified children could get care free of charge as long as they lived in an institution, creating a perverse incentive for families to institutionalize children with severe disabilities. In 1982 Congress mandated that Medicaid-eligible children with disabilities who required an institutional level of services could get personal care and medical services in the home as long as care in the home was appropriate and the cost of providing services in the home did not exceed the cost of institutional care (U.S. Department of Health and Human Services/ASPE/DALTCP 2000). Twenty states have since adopted the TEFRA option (so-called because it was enacted as part of the Tax Equity and Fiscal Responsibility Act).

**EARLY INTERVENTION AND SPECIAL EDUCATION** Many children with disabilities, especially those with ID/DD, receive services and special education under the auspices of the Individuals with Disabilities and Education Act, which entitles children with disabilities or developmental delays to a free appropriate public education (FAPE) from birth to the age of twenty-two or until they complete high school (U.S. Department of Education/OSERS/OSEP 2009).<sup>11</sup> The Infants and Toddlers with Disabilities component (IDEA: Part C—also known as “early intervention”) provides services and supports to children who have (or are suspected of having) disabilities or developmental delays between their birth and their third birthday. The Assistance for Education of All Children with Disabilities component (Part B, commonly known as “special education”) helps states provide special education and related services to children from ages three through twenty-one.

Any child who, upon evaluation, is found to have at least one of thirteen identified disabilities—autism, deafness, deaf-blindness, emotional disturbance,

hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, or visual impairment—is eligible for services. A school-based team collaborates with the child's family to develop a written individualized education program (IEP). The plan identifies educational goals and the necessary services and supports, which can include preventative medical care, therapeutic services, and long-term care services (Child Welfare League of America 2005; Rosenbaum 2008). In 1998 and 1999 at least eight states—Illinois, Maryland, Massachusetts, New York, Rhode Island, Vermont, West Virginia, and Wisconsin—financed the medical, therapeutic, and long-term care components of special education through EPSDT, which provided a total of between 10 and 34 percent of each state's share of special education funding (Parrish et al. 2004).

In 2008, 21 percent of all Medicaid payments—\$63 billion—were spent on children through EPSDT. (An additional \$10.3 billion was spent on CHIP-funded programs, including Medicaid expansions and stand-alone CHIP programs.) Genevieve Kenney, Joel Ruhter, and Thomas Seldon (2009) estimate that children in the top spending decile (which includes a high proportion of children with disabilities) accounted for 72 percent of all EPSDT spending (more than 14 percent of all Medicaid spending) during the period 2002 to 2005. Per capita spending for full-year enrollees in the top spending decile was almost \$8,000 for that period, compared to \$1,106 for all full-year enrollees. Although it is difficult to estimate precisely how much is spent through EPSDT and CHIP on children with special health care needs or disabilities, as distinct from children in the top decile of spending, \$30 billion would represent a conservative estimate of these costs based on these data.

States and localities have primary responsibility for funding special education programs, with states paying an estimated 46 percent of the cost, localities another 46 percent, and the federal IDEA program about 9 percent. In total, states, localities, and the federal government combined spent an estimated \$115 billion in 2008 to educate special education students—or \$54 billion more than they would have spent to provide these students with a standard education (Parrish et al. 2004).<sup>12</sup>

## POLICIES THAT SUPPORT THE CARE OF ADULTS WITH DISABILITIES AND THE FRAIL ELDERLY

Many adults living with impairments that limit their independence and ability to perform necessary activities of daily living without assistance require long-term services and supports. Impairments range from intellectual and developmental disabilities, which people are either born with or develop in childhood, to physical disabilities and chronic illnesses, which may occur at any age, to the frailty associated with old age.

Institutional and in-home services and supports for elders and for younger adults with disabilities—both ID/DD and non-ID/DD—consist mainly of nonmedical

care, such as homemaker services and personal assistance. These include assistance with ADLs (bathing, dressing, eating, transferring, toileting, and mobility inside the home), with IADLs (which include housework, meal preparation, and bill paying), and with some health-related tasks. As described in chapter 4, these tasks are primarily performed by paid adult care workers.

People with ID/DD need a “combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated” (Larson et al. 2000, 5). In addition to assistance with ADLs, adults with ID/DD often require case management, habilitation, supported employment, transportation, and therapies designed to help integrate them into the community. Assistance for people with ID/DD who live with their families comes in the form of services such as respite care, employment support, and adult day care. In addition, a very small number of family caregivers receive cash payments for their service from family support programs (Rizzolo 2009).

As noted in table 6.6, long-term services and supports are provided by a complex system that includes institutional long-term care and home- and community-based personal care and homemaker services, as well as an array of other community and rehabilitation support services. Most publicly funded long-term care is paid for through Medicaid. Several other laws, including the Older Americans Act (OAA) and the Rehabilitation Act, mandate and partially fund the coordination and provision of services for working-age and older adults with disabilities. The OAA funds nutrition and transportation services and provides some personal care for people who are not eligible for Medicaid-funded services. The Rehabilitation Services Administration (RSA) manages a set of programs designed to integrate working-age adults into the mainstream through employment and to support independent living in the community.

### Recipients and Potential Recipients

According to an analysis of the American Community Survey of 2008, 18.3 million working-age (ages twenty-one to sixty-four) people and 14.2 million older adults (age sixty-five and over) living in the community had a disability. Among working-age people with disabilities, 6.2 million had what is called an independent living disability, meaning that they could not do errands without assistance. Among people over sixty-five living in the community, 6.3 million had independent living disabilities (Erickson, Lee, and von Schrader 2010). In addition, 1.8 million people lived in nursing facilities, of whom 1.5 million were sixty-five or older and 290,000, or about 16 percent, were under age sixty-five (U.S. Census Bureau 2010a).

Most of the 1.8 million people living in nursing homes, and another 1.4 million in community settings, received publicly supported services that were paid for mainly by Medicaid. Medicaid personal care services and Medicaid home- and community-based waivers supported personal care and homemaker services in the homes of eligible people with disabilities (Kaye, Harrington, and LaPlante 2010; Harrington et al. 2009).

TABLE 6.6 / Adults with Disabilities and the Frail Elderly Policies

	Long-Term Care, Institutional	Long-Term Services and Supports, Home- and Community-Based	Other Community-Based Services	Rehabilitation Services
Federal-state	Medicaid: Long-term care provisions require that states finance means-tested care in nursing homes, state hospitals, or intermediate care facilities for people with qualifying disability, chronic illness, or age-related infirmity	Medicaid Personal Care Services (PCS): Option to finance personal care services in the home and community for people meeting state eligibility requirements Medicaid Home- and Community-Based Services (HCBS) waivers: Finance long-term services and supports for people with an institutional level of need or less, including homemaker, home health, personal care, and adult day health services Social Services Block Grant (SSBG): Finances a range of means-tested, community-based services for low-income elderly	Administration on Aging: Provides nutrition services (congregate and home-delivered meals), family caregiver support, supportive services (personal care, homemaker, chore, adult day care), transportation, case management, outreach, disease prevention, and health promotion	Rehabilitation Services Administration: Provides vocational rehabilitation services, supported employment, and independent living programs
State-local			State aging agencies and local area agencies on aging (AAAs) provide an array of community-based services.	States sponsor additional vocational rehabilitation services, supported employment, and independent living programs.

Source: Authors' compilation.

## Care and Support Services Received

In 2007 just under 1 million of the roughly 1.5 million adults with ID/DD received publicly supported care, either in residential facilities, community-based residences, or the home of a family member. About 38,000 received their services in state hospitals, 24,000 in larger congregate care facilities with more than sixteen residents, and 376,000 in a supervised residence such as a smaller congregate care facility, group home, foster/host home, or the care recipient's own home. Another 1 million lived with a family member. Of those, only about half—550,000—received publicly funded assistance in addition to the unpaid care provided by relatives (Prouty, Alba, and Lakin 2008).

In 2005, 1.39 million adults with disabilities also received employment and training services through state and local vocational rehabilitation services, and over 200,000 people with disabilities who were living in the community received training, transportation, housing, personal care, and homemaking services through centers for independent living (U.S. Department of Education/OSERS/RSA 2009).

Services were provided under Title III Part B or C of the Older Americans Act (OAA) to 2.9 million older adults in 2008. Only 9 percent of eligible adults—persons age sixty and older whose incomes fell below 185 percent of the poverty threshold—received assistance with meals. An estimated 22 percent of eligible adults who needed help with transportation got it through these programs (U.S. General Accountability Office 2011).

## Federal and State Policies That Support Care for Adults with Disabilities and the Frail Elderly

Medicaid, a means-tested aid program, is a jointly funded venture between federal and state governments that provides medical assistance to low-income people. Since its inception in 1965, Medicaid has been the primary source of public funding for long-term care services and supports for adults with disabilities and frail older persons.

People who meet the financial eligibility requirements for SSI and the Social Security Administration definition of disability—which covers people with physical and mental disabilities and with chronic illnesses—are automatically entitled to receive Medicaid-funded long-term services and supports. (For a discussion of how disability is defined, see the appendix).

Medicaid was the primary payer for 65 percent of nursing home residents in 2004, and for 34 percent of people receiving any long-term care services (personal assistance and home health services) at home in 2005–2006 (Kaye, Harrington, and LaPlante 2010). Medicare, the national health insurance program for everyone sixty-five and over, as well as for younger adults with disabilities, was the primary payer for 18 percent of nursing home residents and for 35 percent of people receiving long-term care services in the community during this period.<sup>13</sup> Assuming that these rates carried through to 2007, about 2.8 million

receiving long-term care that year were funded primarily by either Medicaid (1.8 million) or Medicare (1.0 million). Over half of people with ID/DD are supported by state programs alone and the other half by Medicaid waiver programs, which we discuss later (Prouty, Alba, and Lakin 2008).

**MEDICAID LONG-TERM CARE: INSTITUTIONAL AND HOME- AND COMMUNITY-BASED CARE** State Medicaid plans must provide institutional long-term care and home health care (as well as the EPSDT program) in order to be eligible for federal matching funds. In 1975 states were given the option to include in-home personal care services (the PCS option) as part of their Medicaid plans. As a condition of getting federal matching funds, states must offer any benefit provided to any beneficiaries in their state Medicaid plan to all Medicaid beneficiaries with comparable conditions. (These are known as the statewide-ness and comparability rules.) In other words, if a state wanted to make less expensive in-home personal care services available to elderly persons who were qualified for or already living in nursing homes, they would also have to offer the personal care services to nursing home-eligible working-age adults who were living independently in the community. Many states chose not to adopt the PCS option out of concern that it would stimulate demand and raise the overall cost of providing long-term care.

The Medicaid waiver authority—passed in 1981—allows states to waive statewide-ness and comparability rules, targeting specific services to particular populations. In 2009 there were 286 separate waivers operating in the fifty states and the District of Columbia, with a total of 1.346 million waiver slots. Another 365,000 people were on waiting lists for oversubscribed waiver services. Thirty-one percent of the waivers and 41 percent of the waiver slots were for people with ID/DD, who also represented 61 percent of those on waiting lists. Forty percent of waiver programs and 47 percent of slots were for people over age sixty-five or for people under sixty-five with disabilities. Waivers for people with physical disabilities, children, people with HIV/AIDS, and people with traumatic brain or spinal cord injuries made up the remaining slots (Harrington, Ng, and Watts 2011a). In 2008 there were 1.362 million waiver slots, and a total of 1.241 million participated in the waiver programs (Harrington, Ng, and Watts 2011b).<sup>14</sup>

Prior to passage of the Medicaid waiver authority, most publicly supported long-term care was delivered in state hospitals, other large institutions, and nursing homes. Between 1967 and 2007, the number of people with ID/DD living in state institutions fell from 195,000 to 36,650. As of 2007, only 9 percent of people with ID/DD still lived in facilities that had more than sixteen residents, while only 21 percent of adults with developmental disabilities were living in any kind of institution (Prouty, Alba, and Lakin 2008). In contrast, 68 percent of older adults receiving long-term care were still living in nursing homes in 2008 (Kaye, Harrington, and LaPlante 2010; Harrington, Carrillo, and Blank 2009).

**OTHER COMMUNITY-BASED SERVICES AND SUPPORTS** Congress passed the Older Americans Act in 1965 in response to a concern that there were insufficient

community social services for elderly people. Today the OAA is considered the principal vehicle for the delivery of nutritional and social services to older Americans. Title III of the OAA—Grants for State and Community Programs on Aging—authorizes the appropriation of funds for formula grants to states. These funds are used to provide supportive assistive services (transportation, personal care, homemaker services, case management, adult day health) and nutrition programs (congregate and home-delivered). A 2000 amendment to Title III added caregiver supports (training, counseling, support groups, and access assistance to local services and respite care) (U.S. General Accountability Office 2010a). All people over sixty years of age are eligible for OAA services, but the services are not entitlements, and lack of funding constrains the delivery of direct services. The OAA requires providers to target those with the greatest economic and social need: low-income people, minorities, people lacking proficiency in English, and rural residents.

State and local aging agencies may administer programs that are funded with a combination of OAA funds, other federal funds from Medicaid or social services block grants, state and local funds, and donations and income-based cost-sharing from participants (Rabiner et al. 2006; O'Shaughnessy 2009).

**EXPENDITURES** Using an estimate of the daily cost of long-term care services delivered in nursing homes and in private homes, along with a range of estimates of the number of people receiving care in each setting in 2004–2005, Stephen Kaye, Charlene Harrington, and Mitchell LaPlante (2010) estimate that the total annual spending on paid long-term care services was between \$147 million and \$181 billion (in 2009 dollars), including both public and private expenditures but not including the economic value of unpaid care.<sup>15</sup> Medicaid expenditures of \$106 billion in 2008 accounted for between 56 and 66 percent of estimated spending, and past estimates attribute about 20 percent of long-term care spending to Medicare (Georgetown University 2007). States spend 21 percent of their total budgets (including federal matching funds) on Medicaid, one-third of which pays for long-term care services (Burke, Feder, and van de Water 2005).

Disaggregating long-term care expenditures another way, between \$113 billion and \$136 billion (depending on the data source) is spent on nursing home care. Just \$33 billion is spent on home- and community-based services, most of which is supplied through home health care agencies and paid for by Medicaid and Medicare (Kaye, Harrington, and LaPlante 2010). Only a small amount of home care is so-called consumer-directed care, given by independent providers under the direction of the care recipient, with most of that paid for directly by the person receiving services. However, as noted in the appendix, the number of people working as consumer-directed independent providers is seriously undercounted in government statistics. The growing significance of consumer-directed personal care services does not show up in official data either. It is also important to remember, as emphasized earlier in this volume, that most long-term care is provided by unpaid family caregivers.

## SUMMARY

This large and complex package of public policies constitutes the core of the care policy landscape in the United States. The components of this package—ECEC, family leave, foster care, policies for children with disabilities, and policies that serve adults with disabilities and the frail elderly—operate across multiple levels of government. They take a variety of forms, providing direct services, granting cash payments, and regulating workplaces and service providers.

We began this chapter with the claim that the policies described here comprise the largest public care initiatives in the United States in terms of number of recipients, level of expenditures, or both. Indeed, as we have demonstrated, these policies serve millions of children and adults. About 4 million children are enrolled in the major means-tested child care programs or in publicly funded early education programs, and children in 3.7 million families receive services subsidized by the federal child care tax credit. In one recent year, between 6 million and 13 million U.S. workers took FMLA-qualified family leaves, about half of which were taken by workers to cope with a serious illness of their own, while the other half were taken to care for newborn children, aging parents, or other family members. Nearly half a million children are served in the public foster care system, nearly 7 million children receive federally funded special education services, and 4 million to 5 million children with special health care needs are enrolled in publicly funded EPSDT services. Furthermore, an estimated 2.8 million adults receive long-term care for which the primary payer is either Medicaid or Medicare, about 3 million elderly people receive services annually from programs authorized under the Older Americans Act, and another 1.8 million working-age adults receive employment assistance services and independent living services from the vocational rehabilitation centers funded by the Rehabilitation Services Administration.

These publicly supported care policies come with a substantial price tag. In one recent year, government expenditures on child care via the two main means-tested programs totaled nearly \$11 billion, while public expenditures on early education amounted to nearly \$10 billion. State and federal expenditures on public pre-kindergarten programs total another \$3.8 billion, and tax credits granted through the federal dependent care credit total \$3.2 billion each year. One state alone—California—spends about \$1.4 billion a year on pregnancy benefits and family leave. An estimated \$28 billion in public dollars is spent each year on health care and services for children with special health care needs. In addition, federal, state, and local governments spend about \$115 billion a year on special education.

Turning to long-term care services for adults with disabilities and the frail elderly, recent estimates put combined Medicaid and Medicare spending on long-term care services in 2008 at close to \$140 billion. And \$1.44 billion in federal funding from the Older Americans Act is spent each year on supportive and nutrition services for the elderly and support services for caregivers, supplemented by the local area agencies on aging (AAAs) with between \$3 billion and \$4.4 billion from other public and private sources.

In short, our current care policy package clearly serves large numbers of recipients and requires substantial public funding. But how well is this complex set of policies working? Are needs being met? Are they being met equitably? In the next chapter, we assess how well these policies are working for people in need of care and for their families, with a focus on disparities by income and by geography.

## NOTES

1. For more detail on the ECEC services and programs described in this chapter, see Gornick and Meyers (2003). We gratefully acknowledge Marcia Meyers, who constructed the ECEC typology we use here.
2. A comprehensive evaluation of the FMLA was completed and published in 2000. Later national data on FMLA coverage, eligibility, and usage are not yet available. In the spring of 2011, the U.S. Department of Labor, Wage and Hour Division, began conducting a replication of the 2000 study; to date, the results of this study have not yet been released.
3. Rhode Island enacted its TDI program in 1942; California enacted its state disability insurance program in 1946; New Jersey's TDI program dates to 1948; New York created its disability benefits law in 1949; and Hawaii launched its TDI program in 1969. After the passage of the PDA in 1978, these programs were required to cover maternity.
4. Typically, the age of emancipation has been eighteen. However as a result of the Fostering Connections to Success and Increasing Adoptions Act of 2008, federal Title IV-E foster care payments may be available for foster youth up to age twenty-one under certain conditions.
5. In the National Children's Health Survey 2007, the Maternal and Children's Health Bureau (MCHB) estimated that there were 14.1 million children under age eighteen with "special health care needs," ranging from the regular use of prescription drugs to health and functional limitations that limited participation in age-appropriate activities. "Children with special health care needs" are defined as those who are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require services beyond those required by children generally. Prevalence estimates vary depending on whether special needs are narrowly defined as tied to limitations in specific types of activities or more broadly defined as in the MCHB definition (Rosenbaum 2008). An estimated 4 million of these children have an activity-limiting impairment that would be considered a disability. In all, 4 million to 5 million children with special health care needs were enrolled in EPSDT, including 2 million with activity-limiting impairments. The American Community Survey 2008 estimated that 3.5 million children between the ages of five and seventeen were disabled (U.S. Census Bureau 2009a).
6. Unfortunately, the disability supplement to the NHIS was conducted only in 1994–1995, so there are no more recent data.
7. Medicaid is a jointly funded federal-state program that finances health care for low-income people. EPSDT, which is best thought of as the pediatric component of Medicaid, is a mandatory Medicaid benefit, meaning that all states must offer it as a condition for receiving federal matching funds. Enacted as an amendment to the Social Security Act in 1967, EPSDT was designed to provide baseline preventive health care for all low-income children (not just children with disabilities) and to identify and treat chil-



- dren who have, or are at risk of developing, physical and mental health conditions that could affect their development and growth.
8. States have the option to structure their CHIP programs so that they provide comprehensive medical services, comparable to EPSDT, or to provide a less comprehensive benefit that does not address the above-average needs of children with disabilities. State CHIP programs do not have to cover the comprehensive range of services mandated under EPSDT and therefore do not provide the full range of services required by children with "special health care needs" (Rosenbaum, Wilensky, and Allen 2008). CHIP funds can be used to set up separate CHIP programs or to expand Medicaid coverage. If used to expand Medicaid coverage, then all Medicaid rules and regulations, including cost sharing and benefits, apply, which means that the CHIP-funded Medicaid expansion program provides comprehensive services equivalent to EPSDT. States have much greater flexibility to set eligibility and benefit levels if the CHIP funds are used to set up separate CHIP programs. In 2008, of the 7.3 million children in CHIP-funded programs, only 2 million were in CHIP-funded Medicaid expansions (Ryan 2009).
  9. Unlike other Medicaid benefits, and unlike CHIP and private insurance plans, EPSDT uses a developmental standard for assessment. Preventive and corrective services are defined as "medically necessary treatment," as they must be to qualify for Medicaid reimbursement.
  10. Disabled children age eighteen or older may also be eligible for SSDI (Social Security Disability Insurance) if their parents have the required contributory history. Once eligible for SSDI, they will be eligible for Medicare after two years. The Social Security Administration refers to this as a "child's benefit" because it is paid on the parent's Social Security earnings record (Social Security Administration 2011).
  11. This was first enacted in 1975 as the Education for All Handicapped Children Act and amended in 1990 with the new name, Individuals with Disabilities and Education Act.
  12. There have been no reliable and comprehensive data on what public schools spend on special education since the Office of Special Education stopped requiring its collection in 1987 (Chambers et al. 1998). One recent estimate suggests that it costs 1.9 times as much to educate a special education student as to educate a regular education student (Parrish et al. 2003). Using the ratio of spending per special education student to spending per regular student estimated by Thomas Parrish and his colleagues (2004), and assuming that this ratio remained constant over the last ten years (Parrish 2010), we estimate that the total amount spent to educate special education students in 2008 was \$115 billion and that the marginal cost was \$54 billion, a number that Parrish himself found reasonable (personal communication, October 30–November 3, 2010).
  13. Although Medicare does not pay for long-term care services, it does provide partial payment for up to one hundred days of rehabilitation in a nursing home following an acute medical episode that requires a hospital stay. Medicare also pays for home health care that involves some medical services in addition to personal care services.
  14. The most recent data available on number of participants are from 2008.
  15. This estimate is probably too low, given that it is based on their calculation of the number of people receiving assistance in institutions and home- and community-based services from the Survey of Income and Program Participation (SIPP), the National Health Interview Survey (NHIS), and the American Community Survey (ACS).