Chapter 7

The Disparate Impacts of Care Policy

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National, state, and local governments provide a complex array of services, benefits, and regulations that support children and adults in need of care and their caregivers. In this chapter, we assess how well the current system is working—and for whom. Assessing the adequacy of U.S. care policy provisions requires identifying a set of standards against which to evaluate these provisions. Yet, as decades of policy analysis scholarship have established, there is no single framework to use in assessing the adequacy of policy provisions. In our case, one approach would be to focus on the efficiency or effectiveness of existing care supports—that is, to assess outputs or outcomes relative to expenditures and other inputs across several areas of care policy. Another would call for surveying care recipients and caregivers to assess the degree to which they judge their needs to be met. Yet another would require establishing some absolute standards—one or more floors below which access to (or receipt of) care supports should not fall—and assessing the extent to which those in need of care and their caregivers have access and supports consistent with those standards. All of these approaches would, of course, require tackling challenging normative questions, especially about who needs and deserves care supports, how much and what kind of care is optimal or acceptable, and what the balance should be between public and private provisions.

A comprehensive evaluation of this large package of care policies, using any of these frameworks, is outside the scope of this project. Instead, we focus on the adequacy of the current system from the vantage point of disparities in the receipt of care. Two axes strike us as particularly consequential: disparities by income and disparities by geography. In the first half of this chapter, we review relevant research to assess the interaction between household income and receipt of care, looking at families with high, low, and middle incomes. In the second half, we draw on policy data gathered for this project to assess the variations in the receipt of care across the U.S. states.

DISPARITIES BY INCOME

Income matters in at least two crucial ways. First, public supports for care are provided against the backdrop of an extensive system of private, market-based options, which only higher-income families and individuals can afford without substantial public support and which are often of superior quality or provide a greater range of choice or control relative to their publicly funded counterparts. For early childhood and care, private options include nannies, babysitters, family day care services, child care centers, and educational programs. Public family (and medical) leave programs supplement those provided by individual employers, which may be part of a standard employee-benefit package or individually negotiated. In adult care, publicly funded long-term care services and supports supplement an enormous and complex assortment of private services, including personal and home care aides, assisted living facilities, and retirement communities that offer a long menu of services for a substantial fee.

Second, some publicly provided care supports are means-tested—that is, they are available only to people with low household incomes. Other services—such as foster care services, early intervention and special education for children with learning disabilities, and maternity-related disability pay provided by state temporary disability insurance programs (see chapter 6 for details)—are available to recipients regardless of income. In other policy arenas, including several early childhood education and care services and long-term care programs, eligibility is conditioned on low income. When recipients are separated by income level, a frequent result is income-related disparities in the quantity and quality of the care and support received. In some policy areas, the use of nonrefundable tax credits leads to further disparities by benefiting only families with incomes high enough to pay income taxes.

These intertwined features of the U.S. care system lead to important and complex disparities. Many high-income families have the financial resources to purchase private services, often with the option of choosing among a range of care options, for example, between in-home and various types of institutional care. In addition, people in high-income households are more likely than their lower-earning counterparts to have access to employer-provided benefits.

Low-income families have fewer options, but they do have access to various means-tested public programs—although being low-income hardly guarantees actual access, let alone satisfactory services. In some cases, means-testing thresholds are set so low that they exclude all but the most impoverished families. Even those who qualify may remain without services because many means-tested programs lack entitlement status, allowing states to control costs by rationing access to care. Moreover, the available level of public support may be insufficient to enable recipients to obtain needed care. Many eligible individuals lack services simply because they (or their family caregivers) are not aware that they are entitled to them. Approximately half of uninsured children, for example, are eligible for public health insurance, but their parents or guardians do not apply for it. And finally, those who do access publicly funded services often find that they are of poor quality.

Not wealthy enough to afford private care and not poor enough for means-tested services, families in the middle of the income distribution often face the most limited options. Their employer-provided benefits are patchy at best, and they are ineligible for many public programs, yet they lack the resources to purchase adequate private care. They cannot afford to take unpaid time off work, but paying for ECEC or long-term care services is likely to cause them substantial financial hardship.

Early Childhood Education and Care

Families face remarkably different levels of support for and access to ECEC services depending on their income levels, yet families at all income levels face challenges in arranging ECEC (Williams and Boushey 2010).[1] As other researchers have reported, low-income families face specific ECEC challenges and inadequacies (Meyers et al. 2004). Most notably, they report the highest ECEC cost burden, yet their children receive the least amount of formal care. Low-income parents are more likely than their affluent counterparts to use informal arrangements, largely because they are less expensive.

In their analysis of 2008 national data sets, Joan Williams and Heather Boushey (2010) define low-income families as those in the bottom third of the income distribution, with income falling below 200 percent of the federal poverty level for a family of three. They define professional families as the 13 percent of families with incomes in the top 20 percent in which at least one adult is a college graduate. The remaining 53 percent represent the middle.

The typical low-income family using center-based care for young children spends 14 percent of its total monthly income on that care—about the same as those using in-home care spend, and much higher than the share of family income paid by middle- and upper-income families (Williams and Boushey 2010). When public support is unavailable or insufficient, many low-income families are forced to rely on a patchwork of unpaid child care. One study of poor working families with children found that 60 percent did not pay for ECEC at all (Meyers et al. 2004).

Family income imposes serious constraints on ECEC decisions. Children in low-income families are less likely than their more affluent counterparts to be enrolled in formal care and/or pre-primary school programs (Matthews 2009; U.S. Department of Health and Human Services/ACF/CCB 2008). One study found that three- and four-year-olds from families with incomes in the top quartile are 23 percent more likely to be enrolled in pre-primary school programs than those in the bottom quartile. Even after controlling for several covariates (such as race, ethnicity, and mother's education, employment, and marital status), more affluent children were still 15 to 16 percent more likely to be enrolled in pre-primary school. Because formal care for young children is associated with better cognitive and school-readiness outcomes, disparities in care during early childhood may exacerbate income inequality later in life (Meyers et al. 2004).

While a number of publicly available, means-tested, publicly supported ECEC programs are available to low-income families, many do not take advantage of these services. Although the total amount of federal money for child care doubled in recent years, fewer than one-quarter of eligible children received a subsidy. Among low-income parents, only about 30 percent using center-based care and 15.5 percent using an in-home care center (what is often referred to as "family day care") received a government subsidy. Take-up rates are low in part because public child care subsidies are often low and unstable (Williams and Boushey 2010). Child care vouchers for women who have left welfare to enter the job market pay only $2 an hour, and families often receive the subsidies only briefly, for an average of three to seven months.

Another powerful explanatory factor is that many states ration ECEC by implementing policies that depress demand (such as high copayments and long waiting lists) or supply (such as low provider reimbursements). This explains why Head Start does not fill the gap in pre-primary enrollment that exists between low- and high-income children. The Head Start program is intended to serve poor children, but with income eligibility capped at a stringent $17,170 for a family of three for at least 90 percent of enrollees, it excludes many families in the bottom third of the income distribution. Further, states have no legal obligation to serve all income-eligible children. As a result, a recent GAO study found that 90 percent of more than 550 Head Start programs surveyed had wait lists, and eligible families often waited months to be placed in the program (General Accountability Office 2010b). In total, Head Start serves less than half of all income-eligible four-year-olds and far fewer eligible children below that age (U.S. Department of Health and Human Services/ACF/OHS 2010).

Middle-income families also face serious difficulties, because they do not qualify for government assistance. High-quality care, which can cost as much as $12,000 a year, lies out of reach. Yet the care services they do purchase, costing on average about $126 per week, account for about 11 percent of total family income (Williams and Boushey 2010, 46–47). The Child and Dependent Care Tax Credit (CDCTC) provides a federal tax benefit to offset out-of-pocket care expenses. However, families can claim only a percentage of the expenses incurred, subject to a ceiling. As a result, the benefits remain modest (National Association of Child Care Resource and Referral Agencies 2009).

Family Leave

As in the case of ECEC, the adequacy of family leave provisions is also stratified by income, for three reasons. First, the coverage and eligibility rules of the Family and Medical Leave Act (FMLA)—the main national policy in the United States that provides family leave rights—disproportionately exclude lower-income workers. Second, access to employer-provided leave rights and benefits—and particularly to paid leave benefits—is distributed regressively, rising with both workers' earnings and their household income. Third, workers in low-income families are less likely than others to utilize unpaid leave because they cannot afford to go without a regular paycheck.

A number of weaknesses in the FMLA cut across income groups, compromising its protections even for the most advantaged workers and their families. The definition of family members is narrow—many states limit leaves to the care of spouses, children, and parents, excluding domestic partners and other relatives (such as in-laws). In addition, in most states FMLA-covered medical leave is limited to "serious illness," so routine doctor visits are not grounds for leave-taking, and leaves for other (nonmedical) family care needs, such as attending school meetings, are not covered.

The millions of low-income workers who are not covered under the FMLA negotiate a "high-wire balancing act" (Newman 2000, 90). Access to FMLA leave depends on several factors. First, employees must work in a covered establishment—that is, one with at least fifty employees (employed within a seventy-five-mile radius). Thirty-four million American workers—about 30 percent of the workforce—are not covered by the FMLA because their employers are too small (U.S. Small Business Administration 2010). Second, eligibility requires a record of at least twelve months with the current employer, including at least 1,250 hours worked during the previous year; more than one-fifth of those in covered establishments are ineligible on this count (U.S. Department of Labor 2000). Low-earners are less likely than high-earners to work for larger employers and are also less likely to meet the employment history requirements; as a result, they are overrepresented among those not covered or not eligible for FMLA leave.

Disparities in FMLA coverage and eligibility are compounded by low levels of compliance with the law, which recent estimates place at less than 77 percent and possibly as low as 54 percent (Gerstel and Armenia 2009). Workers who know their FMLA rights can sue employers that violate the law, but such suits are risky and expensive; as a recent study shows, low-wage workers in the United States are particularly vulnerable to labor law violations (Bernhardt et al. 2009). In addition, research in California shows that low-income workers are much less likely to be aware of the FMLA and other leave benefits than are middle-income or high-income workers (Milkman and Appelbaum 2004).

Currently, only about 8 percent of private-sector workers are offered paid leave benefits by their employers (Levine 2009). Employer-provided rights and benefits in the private sector may be offered as part of a standard employee benefit package or may be negotiated on a case-by-case basis. Highly paid private-sector workers are more likely than their low-wage counterparts to enjoy some bargaining power with employers because replacing them is often difficult and costly. Accordingly, access to paid leave declines with wages and household income and is also correlated with educational attainment. Employed women with less than a high school degree, for example, are half as likely to have paid maternity leave as women with a high school diploma, and one-fourth as likely as women with a college degree or higher (Smith, Downs, and O'Connell 2001).

Including the public-sector workforce, where access to paid leave benefits is much more prevalent, only 22 percent of poor families have access to four weeks of paid leave some or all of the time, compared to 59 percent of non-poor families (Heymann 2001). The share of working parents with access to any paid leave is less than 46 percent for those with poverty-level income but over 83 percent for those with incomes at or above 200 percent of the poverty threshold (Ross Phillips 2004). And women with earnings in the top decile are seven times as likely as those with earnings in the bottom decile to have employer-provided paid family leave (Levine 2009).

In addition to these limitations on access to paid and unpaid leave benefits, economic constraints reduce the likelihood that parents will use the unpaid leave time to which they are entitled. Among those parents who take FMLA-guaranteed leaves to care for newborns, more than two-thirds take fewer than half of their allowable days. Nearly 80 percent of employees who do not take FMLA leave when needed report that the reason was that they "could not afford to take leave" (U.S. Department of Labor 2000). The data do not indicate what respondents mean by "could not afford"; some might be in low-income families, while others could be higher earners deterred by opportunity costs. Nevertheless, it is clear that the absence of wage replacement seriously disadvantages low-income workers and their families. As of 2000, about 10 percent of FMLA users who did not receive full pay went on public assistance during their leaves (U.S. Department of Labor 2000). Analysis of vital statistics data shows a small but significant reduction in infant mortality rates among college-educated married mothers attributable to unpaid family leave provisions. No such benefits are apparent for children of other mothers, largely as a result of low take-up rates (Rossin 2011).

Foster Care

Foster care, like many other areas of child welfare policy, is "universal," with state child welfare agencies legally required to protect and serve all children regardless of income. Nevertheless, the foster care system predominantly serves children from low-income families—and too often reproduces their economic disadvantages. Although the foster care system serves children from a wide range of family backgrounds, children from low-income families are far more likely to be placed in foster care than their higher-income counterparts. Children in families with incomes below $15,000 are twenty-two times more likely to be the subject of reported abuse and neglect—and forty-five times more likely to be victims of substantiated neglect—than children in families with incomes above $30,000 (Hutson 2001; Lindsey and Klein Martin 2002). These disparities may be due, to some extent, to inequalities in reporting and investigation of abuse and neglect claims, but poor children are understood to be at higher risk for physical and sexual abuse than children from middle-class and affluent families (Stukes Chipungu and Bent-Goodley 2004). Their higher risk may be the result of basic differences in resources or time, family structure, workforce participation, the criminal justice system involvement of parents or other involved adults, or the stress associated with poverty (Paxson and Waldfogel 1999; Waldfogel 2000; Hutson 2001).

In addition, important income disparities emerge among foster parents, especially between kin and nonkin foster parents. Kin care, which currently makes up roughly 20 percent of formal foster care placements, refers to the placement of a child either with a family member or with someone with whom the child has a significant relationship. Because foster children are disproportionately poor, and because poor children often have poor extended families, kin foster parents are, on average, more economically disadvantaged than are nonkin foster parents. One study estimated that 39 percent of kin foster parents have incomes below the federal poverty line (FPL), compared to only 13 percent of nonkin foster parents (Ehrle and Geen 2002). Kin caregivers are also much more likely than nonkin caregivers to have less than a high school degree (24 versus 13 percent), to be single (58 versus 27 percent), and to be over sixty years old (20 versus 11 percent) (Macomber, Geen, and Main 2003; Grimm and Darwall 2005; U.S. Department of Health and Human Services/ACF 2010). Yet kin foster parents often receive lower levels of public support than foster parents who are not biologically related to the children they care for. (See the later discussion of foster care disparities by geography for details.)

A third key issue concerns the outcomes of the estimated 30,000 youth who age out of foster care each year (U.S. Department of Health and Human Services/ACF/ACYF 2008). Researchers and policymakers have long been concerned about the degree to which tenure in foster care is linked to substantial hardship and poor life outcomes, including a significantly increased likelihood that former foster children will become impoverished adults relative to their peers, even those from similar backgrounds. The system's capacity to provide for the health, education, and developmental needs of the children in its care and to help them transition into adulthood is of particular concern with respect to those who are in foster care for a substantial part of their childhood. In making the transition from the foster care system to independent living, many of these youth find it difficult to find and keep a job or a place to live, and many become pregnant at an early age. An increased likelihood of mental health or substance abuse problems and of insufficient education or job preparedness compounds their difficulties, and a disproportionate number wind up poor, homeless, or incarcerated (U.S. General Accountability Office 1999; Lenz-Rashid 2004).

Many studies have found that there is a direct relationship between participation in the foster care system and employment and criminal justice outcomes for former foster children. Youth aging out of foster care are less likely than other young adults to work during the two years following their emancipation, and when they do work they have significantly lower earnings (George et al. 2002). Another study found that former foster children age twenty-three and twenty-four are less likely than their age-comparable counterparts to be employed and more likely to be poor, and that those who have jobs earn less. Fewer than half of the former foster youth surveyed had a checking or savings account, and almost one-third had low or very low food security. Three-quarters of the women and one-third of the men received benefits from one or more need-based government programs. They also had much higher levels of criminal justice involvement than their peers: 20 percent of women and 42 percent of men reported having been arrested, and 8 percent of women and 23 percent of men reported having been convicted of a crime (Courtney et al. 2010). Other studies document similarly bleak results (Tweddle 2007).

Services for Children with Disabilities

Services for children with disabilities come closer to meeting their needs and mitigating income disparities than do most other services targeted toward children—or toward adults with disabilities. One of two key services, Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), is a means-tested program (see description in chapter 6). However, many states have either set their income eligibility thresholds and income disregards high enough to cover a substantial number of children under EPSDT or have created state-financed programs to serve children whose household incomes are too high to qualify for EPSDT.

States have the option to set income eligibility levels for EPSDT as high as 300 percent of the federal poverty line, and other federal programs provide them with incentives to do so. Both Medicaid and the Children's Health Insurance Program (CHIP) give states some flexibility when they evaluate income eligibility, allowing them to create deductions and disregards for parents of children with disabilities. Further, the individual educational plans (IEPs) for school-age children and individual family services plans for preschool children required by the Individuals with Disabilities Education Act (IDEA) can include medical and therapeutic services for children with developmental delays. As a consequence, IDEA provides an incentive for states to set higher income eligibility thresholds or income disregards so that Medicaid EPSDT will share in the cost of providing mandated medical and therapeutic services (Rosenbaum 2008). As will be discussed in the following section, Medicaid coverage for adults is more limited because there are no similar incentives to raise income eligibility levels for adults.

Certainly disparities are linked to family income, but these are mitigated by the design and accessibility of services for children with disabilities. A recent study found that lower-income children with disabilities who are enrolled in EPSDT actually fare better than middle-income children with private health insurance. The study found no significant differences between the two groups in use of either supportive services for the family (personal care, respite, and transportation) or therapeutic services for the children (speech therapy, therapies for learning disabilities and behavioral problems, and physical therapy), both in and out of school. However, children who had public EPSDT insurance were two to three times more likely to use these services than either children without insurance or children with private insurance, after controlling for numerous other factors that would affect service use (Benedict 2006).

Another key program for children with disabilities, special education, is an entitlement for all children regardless of income. However, as will be discussed in more detail later, huge differences in spending both across and within states prevent all children from having equal access to its services, and inequalities by income play a significant role alongside differences across geography. Federal allocations for special education are made using a formula that takes into account both the number of children enrolled in special education and the state poverty rate. Within states, spending is based on a range of formulas, some of which result in local allocations that are not proportionate to the level of need among school districts (Parrish 2010).

Policies for Adults with Disabilities and the Frail Elderly

Support for long-term care for adults is more stratified by income than is support for the care and education of disabled children. As with ECEC, many upper-income people in need of care (and their families) can afford to purchase private services, and many are able to purchase high-quality care consistent with their preferences (such as home-based rather than institutional care). Low-income people in need may receive long-term care services through the means-tested Medicaid program, the largest purchaser of long-term care services in the United States, but they are more likely than those paying privately to be placed in a nursing home. As with ECEC, middle-income families are largely left to "make do" and typically cobble together a patchwork of unpaid care and purchased services or spend down their assets and rack up expenses until they qualify for Medicaid. This spend-down and the resulting access to benefits often happens only as a result of placing a family member in a nursing home: while only one-fifth of nursing home residents are Medicaid recipients when they enter, Medicaid is the primary payer for four-fifths of residents who stay longer than three years (Kaye, Harrington, and LaPlante 2010).

Upper-income families clearly have the most options, but they still face constraints and challenges. Many find it difficult to arrange care for a parent, spouse, or child because of the demands of jobs with long work hours and inflexible schedules. And for all but the most affluent families, the costs are a substantial burden. The average cost of a year in a nursing facility in 2009 was $79,935 for a private room and $69,715 for a shared room; one year in an assisted living facility cost $37,572. Home health care purchased through an agency cost $21 per hour on average, and "homemakers/companions" cost about $19 per hour in 2009 (Metlife Mature Market Institute 2009).

Low-income people in need of care face a substantially different landscape because many of them are eligible for Medicaid. Although Medicaid provides coverage for long-term care services, drawing on Medicaid to pay for long-term care can put other members of a family in financial jeopardy because they are forced to choose between their own comfort and that of their loved one. For example, for the last twenty years the Centers for Medicare and Medicaid Services has allowed spouses of Medicaid recipients in nursing homes to retain some of their assets, but in many states there is no spousal asset protection if a Medicaid recipient opts for home- and community-based care (O'Brien and Merlis 2007). This has created a perverse incentive: many people who are low-income but who hold some assets choose nursing home care when they would prefer to stay at home (and staying at home would mean lower costs to the state) in order to avoid impoverishing their spouse.

Many middle-income families (who, for the most part, fail to qualify for Medicaid) face an especially restricted set of options. Some have no health insurance coverage, and even for those who do, many health insurance plans—including Medicare—do not include many long-term care benefits. Unfortunately, most middle-income families encounter the need for long-term care as a sudden and catastrophic event for which they have done little, if any, planning, and they are left to navigate a confusing and fragmented system on their own. Unlike other large expenses in people's lives that are likely to be financed through long-term borrowing (such as houses and cars), paid for with insurance (damage from floods, fires, or automobile accidents), or planned for and financed with savings (retirement), most Americans have little idea how they will pay for long-term care if and when they need it. A 2006 survey by AARP showed that 59 percent of Americans over the age of forty-five believed that Medicare would pay for an extended stay in a nursing home, and 52 percent believed that Medicare covers assisted living costs, neither of which is true. Only 11 percent had long-term care insurance (Barrett 2006). Yet people who earn too much to qualify for Medicaid and do not have long-term care insurance must either pay for care out-of-pocket, rely on unpaid care from family members, or both, forcing many to do without needed care.

In addition, even unpaid care can strain a family's finances, since family caregivers must often give up a paying (or better-paying) job or reduce the hours they work for pay in order to care for a relative. That lost income can threaten the economic security of all but the most affluent families.

DISPARITIES BY GEOGRAPHY

Several factors lead to widespread variation across states in access to, and receipt of, care services and supports. The most powerful factor is the federalist governmental structure in the United States, which leaves a substantial degree of policymaking to the states. As we reported in chapter 6, some care-related policies are purely federal, but the vast majority of care-related policies and programs have large state components. Some policies operate as federal-state matching programs, while others function as federally funded block grants. Some state programs extend the eligibility and benefits granted through national policies, while others operate as autonomous state programs. In some cases, uniform rules about eligibility and benefits are set at the national level, but variation across states in administrative and implementation practices leads to extensive cross-state variation in take-up—which, in turn, results in state-to-state variability in de facto access to and receipt of care.

In practice, nearly all elements of early childhood education and care have large state-based components. Paid family leave policies are devised almost entirely at the state level, and many states have expanded access to unpaid leave beyond the protections provided under the federal FMLA. Although the federal government plays a role in funding and influencing some aspects of foster care policy, many key features, such as the maintenance rates paid to families and the treatment of kin care, are determined at the state level and vary widely from state to state. And even though national Medicaid rules require that all state Medicaid programs provide nursing home care and medically necessary home health care, states vary greatly in the other publicly funded long-term care services and supports that they provide for children and adults with disabilities and for the frail elderly.

Furthermore, state-to-state variation in demographic, labor market, and other economic factors can compound state policy differences. All in all, the adequacy and availability of supports for those in need of care, and for their families, varies enormously depending on their state of residence. In short, where one lives matters—and it matters a lot.

Early Childhood Education and Care

The adequacy of ECEC services for America's young children, especially those in low-income homes, depends in no small part on where a child lives. As described in chapter 6, most governmental support for ECEC comes in one of two forms: means-tested child care subsidies for low-income parents or public prekindergarten programs (including the federal Head Start program and state-level prekindergarten programs). Provisions for both vary markedly across the states.

Expenditures on means-tested assistance for child care, including the Child Care and Development Fund (CCDF) and additional funding allocated from the Temporary Assistance for Needy Families (TANF) program, totaled nearly $11 billion in 2006. With about 2 million low-income children served, spending per child served totaled just under $5,400. However, per child spending varied enormously across the fifty states, from a high of $13,972 in Connecticut to a low of $2,066 in

Mississippi—a nearly sevenfold difference (see table 7.1). Nationwide, about one-fifth of poor children under the age of fourteen receive child care services subsidized through CCDF or TANF. That percentage also varies sharply across the states. As of 2006, in three high-enrollment states (Vermont, Wyoming, and Delaware) 35 percent or more of poor children were served, while in another five states (Colorado, South Carolina, Texas, Nevada, and Arkansas) fewer than one-tenth were served.

The adequacy of public early education programs is also largely determined by the state in which a young child lives (see table 7.1). Public expenditures on early education (Head Start and public prekindergarten programs together) amounted to nearly $10 billion in 2006. About 2 million children were served, for an average expenditure of just over $5,400 per child, but state average expenditures per child ranged from a high of $13,717 in New Jersey to a low of $2,860 in Kansas.

The share of young children served in these early education programs also varies considerably by state. Nationwide, about one-tenth of all children under the age of five are enrolled in either Head Start (which is means-tested) or a state-based prekindergarten program (most of which have some income requirements).[2] Again, enrollment levels vary sharply across the states. On the high end, nearly one-fifth of young children in three states—Kentucky, Oklahoma, and Vermont—were served in publicly funded programs as of 2006, while fewer than 5 percent were served in Nevada, Utah, and Oregon.

The regulation of ECEC quality also varies. Although American families pay substantial amounts for ECEC, recent research suggests that the quality of much of the care that they purchase is not very good. A recent study of ECEC recipients up to age four and a half indicates that only 17 percent experienced high-quality care, while another 24 percent received care that was moderately high-quality. More than one-third (35 percent) experienced low-quality care, and 24 percent encountered moderately low-quality care. In other words, more than half experienced low- or moderately low-quality care, and twice as many experienced low-quality as high-quality care (Vandell et al. 2010). This uneven care quality is due in part to the weakness and variability of state regulation.

Because informal babysitters and small family day care homes are exempt from regulation in most states, most nonparental care for young children is provided in settings with little or no public oversight. Many states exempt certain types of child care centers from regulation, such as religious centers (thirteen states) and half-day nursery schools (twenty-two states) (U.S. General Accountability Office 2004). Licensing rules are even more inconsistent. Only twelve states require that all family day care centers be licensed; others exempt providers who care for only a few children or providers who receive no public funds (U.S. General Accountability Office 2004). State resources for enforcing these requirements are limited, so an unknown number of family day care homes operate illegally, even in states that require licensing.

Family Leave

With no national law granting paid family leave, public provision of paid leaves has been left entirely to the states. Five states (California, Hawaii, New Jersey,

TABLE 7.1 / Child Care and Early Education, 2006

	Child Care Assistance Subsidies (CCDF and TANF)				Head Start and Prekindergarten Programs			
	Total Spending (in millions of Dollars)	Total Children Served	Spending per Child Served	Poor Children (Under Age Fourteen) Served	Total Spending (in Millions of Dollars)	Total Children Served	Spending per Child Served	Young Children (Under Age Five Served)
United States[a]	$13,550	2,518,077	$5,381	21%	$9,698	1,876,295	$5,439	9%
Alabama	114	29,610	3,857	14	112	20,246	5,507	7
Alaska	51	7,365	6,896	38	115	27,578	4,157	6
Arizona	173	39,176	4,416	13	161	21,673	7,419	11
Arkansas	85	7,381	11,620	**5**	18	3,412	5,398	7
California	***2,256***	***310,323***	7,271	20	***1,088***	218,290	4,987	8
Colorado	98	16,564	5,909	11	105	34,374	3,065	10
Connecticut	164	11,748	***13,972***	12	122	20,703	5,882	10
Delaware	63	14,510	4,338	57	24	2,733	8,653	5
Florida	820	181,700	4,512	32	489	81,631	5,995	7
Georgia	264	70,531	3,740	16	457	62,826	7,269	9
Hawaii	48	12,366	3,910	38	23	4,535	5,078	5
Idaho	37	10,226	3,609	22	24	5,738	4,194	5
Illinois	897	217,478	4,125	48	506	114,915	4,401	13
Indiana	172	35,990	4,778	14	95	24,379	3,903	6
Iowa	104	20,527	5,080	21	83	15,965	5,173	8
Kansas	107	26,119	4,112	24	64	22,409	**2,860**	12
Kentucky	198	31,941	6,191	15	192	52,610	3,655	***19***
Louisiana	118	39,100	3,012	17	235	45,932	5,106	15
Maine	56	7,695	7,319	19	38	6,236	6,115	9
Maryland	172	28,193	6,100	19	200	36,021	5,554	10
Massachusetts	614	70,913	8,654	39	214	37,694	5,670	10
Michigan	553	135,500	4,084	34	317	53,320	5,942	8

Minnesota	201	32,799	6,141	24	90	22,651	3,984	7
Mississippi	82	39,930	**2,066**	21	160	29,342	5,450	14
Missouri	205	47,303	4,340	20	130	38,378	3,383	10
Montana	27	5,100	5,230	15	21	3,723	5,566	6
Nebraska	69	14,453	4,802	28	50	12,013	4,188	9
Nevada	50	6,364	7,784	8	27	5,691	4,753	**3**
New Hampshire	32	8,748	3,673	45	13	4,163	3,238	6
New Jersey	270	42,001	6,432	19	583	42,534	***13,717***	8
New Mexico	80	22,408	3,584	23	58	13,303	4,338	9
New York	1,004	137,679	7,296	18	683	93,467	7,312	8
North Carolina	470	114,822	4,096	30	199	35,564	5,595	6
North Dakota	**15**	**4,698**	3,121	24	17	3,330	5,101	9
Ohio	745	100,099	7,443	20	263	68,795	3,826	9
Oklahoma	153	30,468	5,013	19	323	47,852	6,741	***19***
Oregon	95	22,627	4,133	17	114	9,951	11,468	4
Pennsylvania	650	119,836	5,421	28	265	46,325	5,723	6
Rhode Island	81	11,632	6,950	33	24	4,899	4,812	8
South Carolina	77	20,801	3,711	12	155	34,100	4,533	12
South Dakota	18	5,135	3,412	21	19	4,075	4,569	8
Tennessee	268	54,036	4,962	20	153	28,720	5,329	7
Texas	541	132,783	4,078	10	958	***280,012***	3,420	15
Utah	64	13,985	4,542	14	37	9,332	4,003	4
Vermont	40	8,477	4,669	***62***	23	5,860	3,926	18
Virginia	245	33,017	7,425	15	159	34,070	4,668	7
Washington	396	73,470	5,385	45	140	20,272	6,888	5
West Virginia	73	18,179	4,030	21	148	15,079	9,839	14
Wisconsin	414	66,001	6,270	37	193	47,359	4,069	13
Wyoming	21	6,270	3,323	41	**12**	**2,215**	5,524	6

Source: Authors' compilation of Meyers et al. (2011); U.S. Census Bureau (2000, 2007).
Note: Within columns, minimum values are marked in **bold**; maximum values are ***bolded and italicized***.
[a] Averages are unweighted fifty-state averages.

New York, and Rhode Island) have TDI programs that grant workers some wage replacement in conjunction with pregnancy and childbirth (see table 7.2). Because TDI programs operate within a disability framework, they only offer benefits related to pregnancy or childbirth; they pay no benefits to fathers caring for infants or to workers caring for ill family members.

Two of these five states—California and New Jersey—have also enacted paid family leave programs. Both programs grant infant-care leaves to mothers and fathers, and both grant family leaves for the care of seriously ill family members. A third state, Washington, recently enacted a paid family leave law as well, although it remains unfunded and will not be implemented until 2012. When Washington's program is up and running, it will grant short periods of paid leave to workers, but only to care for infants (see table 7.2).

Although the federal FMLA grants most workers the right to twelve weeks of unpaid family leave per year to care for infants or for ill family members, states also play an important role in unpaid family leave because several supplement the FMLA with more generous unpaid leave laws of their own (see table 7.2). Seventeen states currently extend FMLA protections to firms with fewer than fifty employees, lengthen the leave period to more than twelve weeks a year, relax the job tenure and hours requirement to less than twelve months and/or fewer than 1,250 hours, and/or broaden the definition of family members beyond child, spouse, or parent.

Some states extend unpaid leaves related to pregnancy or childbirth, some extend leave provisions for caring for seriously ill family members, and some do both. (In table 7.2, the former are reported as "maternity leave" and the latter as "family leave.") For example, Hawaii and Montana impose no firm size minimum for workers taking unpaid maternity leaves; Connecticut, Louisiana, and Tennessee extend the unpaid leave duration from three to four months; and Iowa, Montana, New Hampshire, and Washington have no work tenure requirements for maternity leaves. Maine extends unpaid leaves for care of coresident siblings (who are not covered by the FMLA), and Hawaii grants unpaid leaves to care for several uncovered categories of family members: nondependent adult children, grandparents, parents-in-law, grandparents-in-law, stepparents, and so-called reciprocal beneficiaries (persons who have declared their intent to marry but are not legally eligible to do so).

Foster Care

Nationwide, nearly half a million children are cared for in the public foster care system each year. More precisely, 495,816 children were in foster care on the last day of 2006, constituting 7.3 children per thousand (children under the age of eighteen).[3] However, that rate varies notably by state. Fewer than five children per thousand were in foster care in nine states (Utah, New Hampshire, Mississippi, Virginia, New Mexico, Idaho, South Carolina, Texas, and Louisiana) in 2006. In another nine states (West Virginia, Vermont, Alaska, Wyoming, Oregon, Rhode Island, Iowa, Oklahoma, and Nebraska), the prevalence was twice as high, with ten or more children per thousand in foster care (see table 7.3). Some of this variation can be explained by demographic, economic, social, and behavioral differences

TABLE 7.2 / Family Leave, 2010

	Paid Leave for Private-Sector Employees		Unpaid Leave: Extension of FMLA Rights			
	Paid Maternity Leave Benefits	Paid Family Leave Benefits	FMLA Expansion: Firm Size	FMLA Expansion: Leave Length	FMLA Expansion: Tenure or Hours Required	FMLA Expansion: Definition of Family Members Who Can Be Cared For
United States	No	No	FMLA: 50 or more employees	FMLA: 12 weeks	FMLA: 12 months and 1,250 hours	FMLA: child, spouse, parent
Alabama	No	No	No	No	No	No
Arizona	No	No	No	No	No	No
Arkansas	No	No	No	No	No	No
Arkansas	No	No	No	No		No
California[a]	Yes	Yes	No	No		Domestic partner and child of domestic partner; stepparent
Colorado	No	No	No	No	No	No
Connecticut	No	No	No	16 weeks (family and maternity)	1,000 hours (family and maternity)	Civil union partner; parent-in-law; stepparent
Delaware	No	No	No	No	No	No
Florida	No	No	No	No	No	No
Georgia	No	No	No	No	No	No
Hawaii	Yes	No	No firm size requirement (maternity leave)	No	6-month tenure regardless of hours (family leave); no tenure requirement (maternity leave)	Nondependent adult child; grandparent; parent-in-law; grandparent-in-law; stepparent; reciprocal beneficiary (persons who have declared their intent to marry but are ineligible legally)
Idaho	No	No	No	No	No	No
Illinois	No	No	No	No	No	No
Indiana	No	No	No	No	No	No

(*Table continues on p. 156.*)

TABLE 7.2 / *Continued*

	Paid Leave for Private-Sector Employees		Unpaid Leave: Extension of FMLA Rights			
	Paid Maternity Leave Benefits	Paid Family Leave Benefits	FMLA Expansion: Firm Size	FMLA Expansion: Leave Length	FMLA Expansion: Tenure or Hours Required	FMLA Expansion: Definition of Family Members Who Can Be Cared For
Iowa	No	No	4 or more employees (maternity leave)	No	No tenure requirement (maternity leave)	No
Kansas	No	No	No	No	No	No
Kentucky	No	No	No	No	No	No
Louisiana	No	No	26 or more employees (maternity leave)	4 months (maternity leave)	No tenure requirement (maternity leave)	No
Maine	No	No	15 or more employees (family and maternity)	No	12-month tenure regardless of hours worked (family and maternity)	Domestic partner and child of domestic partner; nondependent adult child; sibling who lives with employee
Maryland	No	No	No	No	No	No
Massachusetts	No	No	6 or more employees (maternity leave)	No	Full-time employees with 3-month tenure (maternity)	No
Michigan	No	No	No	No	No	No
Minnesota	No	No	21 or more employees (family leave)		12-month tenure half-time (family leave)	No
Mississippi	No	No	No	No	No	No
Missouri	No	No	No	No	No	No

Montana	No	No	No firm size requirement (maternity leave)	No	No tenure requirement (maternity leave)	No
Nebraska	No	No	No	No	No	No
Nevada	No	No	No	No	No	No
New Hampshire	No	No	6 or more employees (maternity leave)	No	No tenure requirement (maternity leave)	No
New Jersey[b]	Yes	Yes	No	No	No	Civil union partner and child of civil union partner; parent-in-law; stepparent
New Mexico	No	No	No	No	No	No
New York	Yes	No	No	No	No	No
North Carolina	No	No	No	No	No	No
North Dakota	No	No	No	No	No	No
Ohio	No	No	No	No	No	No
Oklahoma	No	No	No	No	No	No
Oregon	No	No	25 or more employees (family and maternity)	No	180-day tenure at 25 hours or more per week (family and maternity)	Domestic partner and child of domestic partner; nondependent adult child; grandparent; grandchild; parent-in-law
Pennsylvania	No	No	No	No	No	No
Rhode Island	Yes	No	No	13 weeks (family and maternity)	No	Nondependent adult child; parent-in-law
South Carolina	No	No	No	No	No	No
South Dakota	No	No	No	No	No	No
Tennessee	No	No	No	4 months (family and maternity)	No	No
Texas	No	No	No	No	No	No
Utah	No	No	No	No	No	No

(*Table continues on p. 158.*)

TABLE 7.2 / *Continued*

	Paid Leave for Private-Sector Employees		Unpaid Leave: Extension of FMLA Rights			
	Paid Maternity Leave Benefits	Paid Family Leave Benefits	FMLA Expansion: Firm Size	FMLA Expansion: Leave Length	FMLA Expansion: Tenure or Hours Required	FMLA Expansion: Definition of Family Members Who Can Be Cared For
Vermont	No	No	10 or more employees (family and maternity)	No	No	Civil union partner and child of civil union partner; nondependent adult child; parent-in-law
Virginia	No	No	No	No	No	No
Washington[c]	No	Yes	8 or more employees (maternity)	No	No tenure requirement (maternity leave)	Domestic partner and child of domestic partner
West Virginia	No	No	No	No	No	No
Wisconsin	No	No	No	No	1,000 hours (family and maternity)	Registered or unregistered domestic partner; parent-in-law
Wyoming	No	No	No	No	No	No

Source: Authors' compilation of National Partnership for Women and Families (2012); State of California/EDD (2010a); State of New Jersey/EPBAM (2010); State of New Jersey/DOLWD (2010b).

[a] California enacted paid family leave in 2002; it came into effect in 2004. The FMLA extension provisions reported here refer to the state's unpaid leave law, which predated the paid leave law and which remains in force. The state's paid leave law has no minimum enterprise size; it also has a less stringent tenure requirement than specified in the FMLA.

[b] New Jersey enacted paid family leave in 2008; it came into force in 2009. The FMLA extension provisions reported here refer to the state's unpaid leave law, which predated the paid leave law and which remains in force. The state's *paid* leave law has no minimum enterprise size; it also has a less stringent tenure requirement than specified in the FMLA.

[c] Washington enacted paid family leave (infant care only) in 2007; the program has not been funded.

TABLE 7.3 / Foster Care, 2004 to 2006

	Population in Foster Care on Last Day of Year (2006)	Children in Foster Care per 1,000 Children Under Age Eighteen (2006)	Children in Out-of-Home Care Who Were Placed in Kinship Care (2004)	Monthly Maintenance Payments: Regular Foster Care, Children Age Nine (2004)	Monthly Maintenance Payments: Specialized Foster Care, Children Age Nine (2004)	Children Waiting for Adoption As Percentage of Children in Foster Care (2006)	Adoptions As Percentage of Children in Foster Care Waiting for Adoption (2006)
United States[a]	495,816	7.3	19%	$450	$950	26%	42
Alabama	7,157	6.4	14	434	1,065	23	**23**
Alaska	1,919	10.7	30	580	808	38	29
Arizona	9,767	6.0	32	n/a	n/a	27	53
Arkansas	3,434	5.0	4	435	**2,625**	27	42
California	***76,405***	8.0	33	494	n/a	24	41
Colorado	8,139	7.0	14	n/a	n/a	26	46
Connecticut	6,359	7.8	19	***717***	2,496	21	48
Delaware	**1,074**	5.3	9	391	1,050	28	31
Florida	29,229	7.3	**44**	364	n/a	26	41
Georgia	13,175	5.4	14	405	n/a	17	54
Hawaii	2,357	7.9	39	529	570	32	53
Idaho	1,850	4.7	16	300	n/a	29	32
Illinois	18,815	5.8	34	n/a	n/a	16	57
Indiana	11,401	7.2	13	468	961	29	35
Iowa	9,040	12.7	**1**	n/a	n/a	16	69
Kansas	6,237	9.0	19	568	2,129	33	26
Kentucky	7,606	7.6	9	591	1,110	27	36
Louisiana	5,213	4.8	11	365	**365**	21	43

(*Table continues on p. 160.*)

TABLE 7.3 / *Continued*

	Population in Foster Care on Last Day of Year (2006)	Children in Foster Care per 1,000 Children Under Age Eighteen (2006)	Children in Out-of-Home Care Who Were Placed in Kinship Care (2004)	Monthly Maintenance Payments: Regular Foster Care, Children Age Nine (2004)	Monthly Maintenance Payments: Specialized Foster Care, Children Age Nine (2004)	Children Waiting for Adoption As Percentage of Children in Foster Care (2006)	Adoptions As Percentage of Children in Foster Care Waiting for Adoption (2006)
Maine	2,076	7.4	15	n/a	n/a	33	48
Maryland	9,051	6.6	33	n/a	n/a	n/a	n/a
Massachusetts	11,499	7.9	17	546	n/a	24	32
Michigan	20,142	8.1	32	n/a	n/a	31	42
Minnesota	6,827	5.4	21	524	524	20	49
Mississippi	3,126	4.1	32	355	700	29	28
Missouri	10,181	7.2	21	**277**	657	27	46
Montana	1,909	8.8	34	450	764	32	45
Nebraska	6,187	***13.9***	16	292	n/a	16	55
Nevada	5,068	8.0	20	n/a	n/a	36	24
New Hampshire	1,146	3.8	13	381	n/a	22	54
New Jersey	10,740	5.1	10	453	n/a	**44**	28
New Mexico	2,357	4.6	24	441	620	36	39
New York	29,973	6.6	17	504	1,007	27	35

North Carolina	11,115	5.2	22	$440	n/a	28	40
North Dakota	1,331	9.3	17	397	632	24	47
Ohio	16,631	6.0	15	n/a	n/a	24	45
Oklahoma	11,736	13.1	25	400	900	31	32
Oregon	10,661	12.4	21	393	568	26	39
Pennsylvania	21,135	7.5	19	n/a	n/a	17	54
Rhode Island	2,998	12.6	25	409	n/a	**13**	65
South Carolina	4,920	4.7	6	n/a	n/a	36	24
South Dakota	1,648	8.5	17	415	693	31	30
Tennessee	8,618	6.0	14	495	545	21	56
Texas	30,848	4.7	18	608	1,369	40	28
Utah	2,427	**3.1**	7	418	510	20	n/a
Vermont	1,379	10.3	9	571	900	18	65
Virginia	7,672	4.2	4	365	n/a	23	31
Washington	10,457	6.8	33	446	174	23	51
West Virginia	4,018	10.3	4	600	1,521	26	39
Wisconsin	7,459	5.7	31	329	n/a	16	***73***
Wyoming	1,304	10.8	15	400	400	16	27

Source: Authors' compilation of data from Child Welfare League of America (2005); U.S. Census Bureau (2007); U.S. Department of Health and Human Services/ACF/ACYF/CB (2009a, 2010).

Note: Within columns, minimum values are marked in **bold**; maximum values are ***bolded and italicized***.

n/a = not available

[a] U.S. value represents the unweighted fifty-state averages.

across states that affect the need for care, but some is clearly explained by variability in the performance of public foster care systems. However, drawing direct connections between the variation in foster care utilization and the specific practices of given states or localities is beyond the scope of this book.

That said, one especially consequential aspect of foster care policy varies markedly across the states and deserves attention, not least because it relates directly to income disparities: that is, the funding available to foster parents to provide for the children in their care. Recent research indicates that these so-called maintenance rates are often inadequate, particularly the regular (nonspecialized care) rates. Inadequate maintenance rates make it difficult to attract and retain high-quality foster care homes (National Association of Public Child Welfare Administrators 2007; DePanfilis et al. 2007). Maintenance payments vary widely from state to state (see table 7.3). In 2004 regular foster care payments for nine-year-old children average from $277 in Missouri to $717 in Connecticut. (These payment rates are cost-of-living-adjusted.) That same year, specialized foster care payments for nine-year-olds with special needs were substantially higher, averaging $980 a month across the states and ranging from less than $500 in Louisiana and Wyoming to more than $2,000 in Kansas, Connecticut, and Arkansas.

One of the most crucial and complex issues in foster care policy concerns the placement of children in kin care. Historically, many child welfare agencies were hesitant to embrace kin care, both because it makes adoption more difficult and because it was believed that children in kin care could remain vulnerable to abuse from their biological parents. However, child welfare analysts have increasingly called for expanding and supporting kin care options, on the grounds that kin care can lessen the trauma of removal, help maintain family connections, and add caregivers and flexibility to a system in which foster homes are often in limited supply, especially on short notice (Center for Law and Social Policy/ABA 2010). Policies promoting and supporting kin care have been adopted by many states, and a preference for it is stated in the 1996 federal welfare reform law (Jantz et al. 2002; Child Welfare League of America 2005; DiNitto and Cummins 2005; Geen 2004).

In 2004 kin care made up about one-fifth (19 percent) of all formal foster care placements nationwide. This percentage varied from 35 percent or more in Hawaii and Florida to less than 5 percent in Iowa, Arkansas, West Virginia, and Virginia (see table 7.3). These official foster care placements do not include the more than 2 million children nationwide living with relatives other than their parents in informal kinship care arrangements (Geen 2004).

States may use waivers and variances to relax foster care rules associated with federal (Title IV-E) payments in order to better incorporate kin care into their foster care programs—and many do. As of 2003, kin were required to meet the same standards as nonkin foster parents in only fifteen states, while twenty-three applied nonkin licensing standards to kin but waived or modified one or more standards for nonkin parents. Twelve of these states allowed waivers concerning minimum household space, eleven waived some or all training requirements, and eight waived minimum age requirements. A few waived requirements related to transportation resources (for example, owning a car), family structure, and educational attainment. Other states offered an entirely separate approval process for kin, which was almost always less stringent than that for nonkin (Geen 2003).

Unfortunately, relaxed licensing requirements for many kin foster parents often go hand in hand with lower maintenance payments—or none at all. Foster parents who do not meet all the Title IV-E licensing standards established in a state's plan are not eligible for federal foster care payments. States often use state or local funds to offer maintenance payments of their own, but these may not be equivalent to their maintenance payments for licensed caregivers (Center for Law and Social Policy/ ABA 2010). In twenty-six states, at least some kin are not eligible to receive maintenance payments. Six states provide state-funded foster care payments to kin who meet standards that are different from those for nonkin foster parents (Geen 2003).

Finally, children in foster care face markedly different outcomes across the states with respect to their exit from the foster care system, particularly as regards adoption. In 2006, 26 percent of the children in foster care were designated as waiting to be adopted, ranging from as low as 13 percent in Rhode Island to as high as 44 percent in New Jersey. In that same year, across the states, 44 percent of children in foster care who were waiting for adoption were in fact adopted. Rates of adoption (among those waiting for adoption) also varied widely, from just under one-quarter (23 percent) in Alabama to a remarkably high three-quarters (73 percent) in Wisconsin (see table 7.3).

Very little research has been conducted on the factors that shape these cross-state differences in adoption rates out of foster care, so it is difficult to discern the extent to which policy variation across the states explains these widely varied outcomes. However, a team of social policy researchers recently surveyed state adoption managers about barriers to the adoption of children in the foster care system (Wilson, Katz, and Geen 2005). This survey, to which forty-three states responded, produced some tentative explanations and showed that states vary markedly with respect to several factors thought to be consequential. These include the number of public agency staff assigned to adoption, the structure of the outreach process, and the relative balance struck by state administrators between encouraging prospective parents and screening out those judged to be inappropriate.

Policies for Children with Disabilities

As discussed earlier, children's participation in Medicaid EPSDT and/or CHIP, and in the non-means-tested Early Intervention (IDEA: Part C) and Special Education programs (IDEA: Part B) is high, in part because these programs use a much broader definition of disability than adult programs and in part because enrollment is encouraged through the public school system. Nonetheless, there is still considerable variability in enrollemnt across states.

COMPREHENSIVE HEALTH CARE—MEDICAID EPSDT AND CHIP Nationally, 36 percent of children age zero to eighteen are enrolled in Medicaid and/or CHIP (see table 7.4). However, statewide participation rates range from highs of 66 percent

TABLE 7.4 / Medicaid Programs for Children: Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) and Children's Health Insurance Program (CHIP), 2007 to 2009

	Medicaid-CHIP Participation (FY 2007) As Percentage of Population Age Eighteen and Younger (2008–2009)	Medicaid-CHIP Participation As Percentage of Eligible Population (FY 2007)	Medicaid-CHIP Payments per Enrollee (FY 2007)	Income Eligibility Levels for Children's Regular Medicaid and Children's CHIP-Funded Medicaid Expansions As Percentage of Federal Poverty Level (2009)[b]		
				Infants Age Zero to One	Children Age One to Five	Children Age Six to Nineteen
United States[a]	36%	82%	$2,298	133%	133%	100%
Alabama	37	85	2,155	**133**	**133**	**100**
Alaska	38	74	**4,261**	150	150	150
Arizona	37	77	4,092	140	**133**	**100**
Arkansas	50	88	1,846	**133**	**133**	**100**
California	43	82	1,445	200	**133**	**100**
Colorado	25	69	1,723	**133**	**133**	**100**
Connecticut	32	85	2,527	185	185	185
Delaware	36	84	2,225	185	**133**	**100**
District of Columbia	**66**	**95**	2,740	185	**133**	**100**
Florida	34	70	1,665	185	**133**	**100**
Georgia	36	81	2,000	200	**133**	**100**
Hawaii	31	91	2,111	**133**	**133**	**100**
Idaho	30	74	1,728	**133**	**133**	**100**
Illinois	39	88	2,602	**133**	**133**	**100**
Indiana	35	81	1,899	**133**	**133**	**100**
Iowa	30	87	1,675	**133**	**133**	133
Kansas	27	81	2,234	150	**133**	**100**
Kentucky	36	90	2,399	185	**133**	**100**
Louisiana	52	89	**1,192**	**133**	**133**	**100**
Maine	43	92	2,698	**133**	**133**	125
Maryland	27	87	2,590	185	185	185
Massachusetts	29	**95**	4,064	185	**133**	114

Michigan	41	90	1,622	185	150	150
Minnesota	30	81	2,714	275	275	275
Mississippi	45	81	1,659	185	**133**	**100**
Missouri	36	85	2,807	185	**133**	**100**
Montana	26	69	2,406	**133**	**133**	**100**
Nebraska	30	83	2,579	**133**	**133**	**100**
Nevada	19	**55**	1,938	**133**	**133**	**100**
New Hampshire	28	86	2,816	185	185	185
New Jersey	23	81	2,305	200	**133**	**100**
New Mexico	56	81	2,664	185	185	185
New York	42	89	2,344	200	**133**	**100**
North Carolina	35	85	2,525	200	200	**100**
North Dakota	23	75	1,908	**133**	**133**	**100**
Ohio	37	83	1,672	150	150	**100**
Oklahoma	44	81	2,251	**133**	**133**	**100**
Oregon	29	75	2,061	**133**	**133**	**100**
Pennsylvania	32	86	2,656	185	**133**	**100**
Rhode Island	37	84	3,542	185	**133**	**100**
South Carolina	40	79	2,036	150	150	**100**
South Dakota	35	82	2,182	**133**	**133**	**100**
Tennessee	46	87	2,165	185	**133**	**100**
Texas	37	75	2,400	185	**133**	**100**
Utah	**17**	66	2,434	**133**	**133**	**100**
Vermont	49	94	2,209	***300***	***300***	***300***
Virginia	23	81	2,015	**133**	**133**	**100**
Washington	38	83	1,927	200	200	200
West Virginia	45	89	2,348	150	**133**	**100**
Wisconsin	30	87	1,269	***300***	185	**100**
Wyoming	36	78	2,038	**133**	**133**	**100**

Source: Authors' compilation of data from Kaiser Family Foundation (2010).

Notes: Children are individuals from birth to age nineteen. Within columns, minimum values are marked in **bold**; maximum values are ***bolded and italicized.***

[a] Unweighted fifty-state averages.

[b] U.S. figure is the federal minimum eligibility level.

in the District of Columbia, 52 percent in Louisiana, and 49 percent in Vermont to lows of 19 percent in Nevada and 17 percent in Utah. The second column in table 7.4 reports the percentage of children eligible for public medical insurance who participate in the programs. That number ranges from a high of 95 percent in the District of Columbia and Massachusetts to the very low rate of 55 percent in Nevada. (Six more states—Hawaii, Kentucky, Maine, Massachusetts, Michigan, and Vermont—report participation rates of 90 percent or higher.)[4]

State-to-state differences in eligibility requirements and in the efforts made to enroll eligible candidates account for state variability in enrollment rates for eligible children.[5] Under Medicaid regulations, state Medicaid agencies must not only pay for preventive and corrective care for children but also ensure that children actually get needed care by providing administrative care management in concert with other public agencies—especially maternal and child health, other public health agencies and schools, and other means-tested programs such as the Supplemental Nutrition Assistance Program (SNAP, or food stamps). This outreach is effective: one study found a participation rate of 93.5 percent among eligible poor children who lived in households that received food stamps, compared to 72.9 percent among those who did not (Kenney et al. 2010). There is also a fairly high positive correlation between the proportion of schoolchildren who are receiving special education and the participation rate of eligible children in Medicaid. As explained in chapter 6, if a child enrolled in special education has special health care needs that are cited in the IEP, and that child is eligible for Medicaid, Medicaid must pay for treatment. Thanks to compulsory education and the universal entitlement to special education, children with special health care needs or disabilities have a very good chance of getting the care they need.

The data reported in table 7.4 on spending per enrollee captures average payments for all children enrolled in the Medicaid and CHIP programs. Medicaid-CHIP spending per enrollee in 2007 ranged from a high of $4,261 in Alaska (with Arizona, Massachusetts, and Rhode Island not far behind) to a low of $1,119 in Louisiana (followed closely by Wisconsin and California). No available public data disaggregate state spending on children enrolled in EPSDT and CHIP into those with disabilities and those without. But it seems likely that variation in per-enrollee spending across states derives from considerable variation in the level of services covered and the proportion of children with special health care needs enrolled in EPSDT (Kenney et al. 2010).[6]

Public insurance is especially critical for children with special health care needs. Even after controlling for age, race-ethnicity, income, gender, family structure, primary language, severity of limitation, and whether parents cut back or stopped working because of the child's condition, children who do not have public insurance are far more likely to report that they are unable to get the services they need (that is, to be underinsured), even if they have private insurance. Similarly, underinsurance rates are higher in states with more stringent Medicaid income eligibility requirements, which makes it more difficult to get public insurance. Children in states where the maximum income eligibility level is

100 percent of the federal poverty line are 24 percent more likely to be underinsured than children living in states where income eligibility is set at 200 percent of the FPL (Kogan et al. 2010).

The final three columns in table 7.4 report Medicaid income eligibility levels for EPSDT in each of three age groups. As discussed in the first section of this chapter on disparities in care by income, states must set EPSDT income eligibility requirements at no more than 300 percent of the FPL. Income eligibility is higher for CHIP than for EPSDT in most states, because CHIP was meant to expand health insurance coverage to uninsured children, either as an expansion of the Medicaid program or as a separate program. However, children enrolled in CHIP do not receive the range of preventive, corrective, and personal care services included under EPSDT; those services have proven critical to the mainstreaming and education of children with disabilities in the most integrated setting possible (Rosenbaum 2008). EPSDT income eligibility levels are therefore a better indicator of the likelihood that children with special health care needs are adequately covered.

States offer targeted services through a wide variety of Medicaid waivers, for which eligibility may be limited to groups with specific disabilities or other characteristics. The utilization of waivers for specific populations varies widely across states. For example, of Colorado's eleven waivers, four are targeted to different groups of children, including two for children with developmental disabilities—one for children with autism spectrum disorders and one for children with physical disabilities. But in Florida, which has twelve waivers, none are targeted specifically to children (Kaiser Family Foundation 2010).

EARLY INTERVENTION AND SPECIAL EDUCATION As shown in table 7.5, about 2.3 percent of infants and toddlers and 8.7 percent of school-age children were enrolled in early intervention and special education (IDEA) programs nationwide in 2004. Participation in early intervention programs among children under age three ranged from 7.1 percent (in Hawaii) to a low of 1.3 percent (in Alabama, the District of Columbia, Nevada, and Georgia). Enrollment in special education programs for children age three through twenty-one varied from a high of 12.2 percent (in the District of Columbia, closely trailed by Maine and Rhode Island) to a low of 6.7 and 6.8 percent (in California and Colorado). Nationally, 13.4 percent of public school children were in special education programs, ranging from about one-fifth of students (19.7 percent) in Rhode Island to about one-tenth (10.1 percent) in Texas.

Federal support for special education is estimated by using a formula based on a combination of each state's prior funding level, its share of students receiving special education, and its poverty rate (Parrish 2010).[7] Federal support per student does not vary dramatically across states, but the federal share of total spending on special education varies considerably because there is so much variation in state and local contributions. Total spending per pupil ranged from $8,196 in Mississippi to $34,529 in Hawaii, for a national average of $17,439. Other states with high expenditures per student included Connecticut, New Hampshire, New York, and Vermont. Notably, New York and Vermont were

TABLE 7.5 / Special Education and Early Intervention for Children: Individuals with Disabilities Education Act (IDEA): Parts B and C, 2004 to 2008

	Children (Birth to Age Three) Enrolled in Early Intervention Services (IDEA: Part C) As Percentage of Population (2004)	Students (Age Three to Twenty-Two) Enrolled in Special Education (IDEA: Part B) As Percentage of Population (2004)	Students Enrolled in Special Education As Percentage of Public School Enrollment (2007–2008)	Federal Special Education Appropriations per Student[a] (FY 2008)	Estimated Total Federal, State, and Local Spending per Special Education Student[b] (FY 2007–2008)	Federal Share As Percentage of Estimated Total Spending (2007–2008)[c]
United States	2.3%	8.7%	13.4%	$1,740	$17,439	10%
Alabama	**1.3**	8.0	11.4	2,175	17,439	12
Alaska	2.0	8.9	13.4	2,153	12,556	17
Arizona	1.5	7.5	12.1	1,435	17,613	8
Arkansas	2.9	9.4	13.8	1,756	14,474	12
California	1.8	**6.7**	10.6	1,873	15,172	12
Colorado	1.7	6.8	10.4	1,877	18,311	10
Connecticut	3.1	8.2	12.1	1,961	26,158	7
Delaware	3.1	9.1	15.9	1,804	17,962	10
District of Columbia	**1.3**	***12.2***	13.9	1,685	n/a	n/a
Florida	1.9	9.5	14.7	1,636	12,207	13
Georgia	**1.3**	8.1	11.5	1,733	19,008	9
Hawaii	***7.1***	7.1	11.4	2,008	***34,529***	6
Idaho	2.7	7.2	10.3	2,004	13,951	14
Illinois	2.9	9.5	15.2	1,605	20,404	8
Indiana	4.2	10.3	17.1	**1,454**	11,161	13

Iowa	2.1	9.9	14.3	1,789	21,973	8
Kansas	2.6	8.8	14.0	1,669	22,322	7
Kentucky	2.3	10.2	16.4	1,516	16,044	9
Louisiana	2.3	8.2	12.9	***2,179***	20,927	10
Maine	2.9	11.9	17.5	1,645	22,496	7
Maryland	2.8	7.6	12.4	1,954	22,671	9
Massachusetts	5.8	10.4	17.3	1,720	17,265	10
Michigan	2.2	8.9	14.0	1,714	13,079	13
Minnesota	1.5	8.6	14.2	1,632	22,496	7
Mississippi	1.7	8.6	13.3	1,851	**8,196**	**23**
Missouri	1.5	9.6	15.1	1,660	15,172	11
Montana	2.1	8.3	12.7	2,116	14,474	15
Nebraska	1.7	9.8	15.7	1,658	19,532	8
Nevada	**1.3**	7.6	11.3	1,472	17,090	9
New Hampshire	2.7	9.5	16.1	1,511	28,251	**5**
New Jersey	2.2	10.9	18.1	1,461	23,368	6
New Mexico	3.4	9.7	14.1	1,997	17,265	12
New York	4.3	9.3	16.4	1,715	28,600	6
North Carolina	1.7	8.7	12.9	1,714	15,172	11
North Dakota	2.8	9.2	14.3	2,104	20,055	10
Ohio	1.8	8.7	14.8	1,641	14,300	11
Oklahoma	2.0	10.2	14.8	1,567	17,962	9
Oregon	1.6	8.4	13.8	1,675	14,126	12
Pennsylvania	3.1	9.2	16.3	1,477	19,357	8
Rhode Island	3.6	11.9	***19.7***	1,562	21,101	7
South Carolina	1.4	10.2	14.6	1,729	14,126	12
South Dakota	2.8	8.6	14.8	1,904	18,485	10
Tennessee	1.7	8.3	12.5	1,956	13,951	14
Texas	1.8	7.9	**10.1**	2,069	12,033	17

(Table continues on p. 170.)

TABLE 7.5 / *Continued*

	Children (Birth to Age Three) Enrolled in Early Intervention Services (IDEA: Part C) As Percentage of Population (2004)	Students (Age Three to Twenty-Two) Enrolled in Special Education (IDEA: Part B) As Percentage of Population (2004)	Students Enrolled in Special Education As Percentage of Public School Enrollment (2007–2008)	Federal Special Education Appropriations per Student[a] (FY 2008)	Estimated Total Federal, State, and Local Spending per Special Education Student[b] (FY 2007–2008)	Federal Share as Percentage of Estimated Total Spending (2007–2008)[c]
Utah	1.8	7.8	10.9	1,757	12,556	14
Vermont	3.2	9.2	n/a	n/a	29,123	n/a
Virginia	1.8	9.0	13.7	1,703	20,927	8
Washington	1.7	7.7	12.0	1,834	14,474	13
West Virginia	3.3	12.0	16.9	1,625	15,172	11
Wisconsin	2.8	9.0	14.5	1,693	17,788	10
Wyoming	4.0	10.3	16.5	2,048	15,869	13

Source: Authors' compilation of data from U.S. Department of Education/NCES/IES (2009), tables 35, 52, 178, and 182; U.S. Department of Education/OSERS/OSEP (2009), tables 1 through 10; Parrish et al. (2004); Parrish (2010); and Chambers, Parrish, and Harr (2004).

n/a = not available.

[a] Includes grants to states, preschool grants, and grants for infants and families (Titles B and C).

[b] Estimated as total national spending per enrolled student (U.S. Department of Education/NCES/IES 2009, tables 178 and 35) multiplied by the ratio of the cost to educate special education students to the cost to educate regular students (Parrish et al. 2004), multiplied by the index of relative state spending (Parrish 2010). Per pupil expenditures to educate special education students = average spending per regular student in 1999–2000 multiplied by the inflation factor multiplied by the ratio of spending on special education to regular students. Average spending per regular student in 1999–2000 = $6,556 (Chambers, Parrish, and Harr 2004, exhibit 2 and table B.3); the inflation factor of 1.40 is estimated by total expenditures per pupil in fall enrollment in 2006–2007 divided by total expenditures per pupil in fall enrollment in 1999–2000, in unadjusted dollars (U.S. Department of Education/NCES 2009, table 182). Ratio of spending per special education student to spending per regular student:

1.9 (Chambers et al. 2004, 5). The number of special education students in 2006–2007 is based on column 1.

[c] "Federal Special Education Appropriation per Student" divided by "Estimated Total Federal, State, and Local Spending per Student" (column 4 divided by column 5).

among the states that used Medicaid funds to finance significant amounts of state spending on special education.

Policies for Adults with Disabilities and the Frail Elderly

Assessing the adequacy of long-term care supports is difficult, but three principle metrics help to clarify the picture: the number of people served relative to the population; the amount spent per program participant in each state; and the balance between home- and community-based and institutional care. All three metrics vary widely across the states both for adults with intellectual and developmental disabilities (ID/DD) and for those with non-ID/DD disabilities.

LONG-TERM CARE FOR ADULTS WITH DISABILITIES OTHER THAN ID/DD AND THE FRAIL ELDERLY In 2006, 10.8 elders and people with disabilities for every thousand in the national population were receiving long-term care services (see table 7.6). Some states, such as Utah, Nevada, and Virginia, provided well below average coverage at only 3.3 to 5.4 people per thousand, while others, such as Arkansas (18.9), New York (16.1), Minnesota (14.4), and California (13.8), covered far more than the national average. States also spent hugely different amounts per participant on long-term services and supports in 2006, ranging from a low of $12,912 in Alabama and Arkansas to a high of $63,812 in Alaska. Variation in actual per-participant spending across states depends both on differences in the amount spent per participant in the same type of setting (nursing homes or non-institutional settings) and on variation in the proportion of long-term care provided in each setting. To capture a measure of relative spending that controls for the latter, state spending per participant is measured as the average spending per participant in each setting, weighted by the national average share of participants in each setting (47 percent in home- and community-based services [HCBS] and 53 percent in nursing homes). Nationally, the weighted average spent per Medicaid participant was $20,451.

Most states moved significantly away from their almost total reliance on nursing homes in the 1960s to a more balanced system that includes extensive agency-provided home care services. The last decade has seen a movement to expand consumer-directed care as well. In consumer-directed care programs, care recipients have the option to control their own service budgets and/or to hire, fire, and supervise their care providers. By 2008, fourteen states offered consumer-directed home care as an alternative to agency-supplied services under the state personal care services (PCS) option, and thirty-five offered some consumer direction through HCBS waivers (Harrington, Ng, and Watts 2009). In other states, consumer direction is being introduced through demonstration projects. The Cash and Counseling program, for example, offers a cash budget that Medicaid consumers can use to pay for a combination of home modifications, assistive devices, or personal care and homemaking services.[8]

Though all states have made at least some progress in this area, there is huge variability among them in terms of the balance between institutional and non-institutional care, as reported in table 7.6. In five states (Alaska, California, Idaho,

TABLE 7.6 / Medicaid Long-Term Services and Supports, for Adults Eighteen to Sixty-Four with Disabilities Other Than Intellectual and Developmental Disabilities and Adults Age Sixty-Five and Over, 2006 to 2008

	Long-Term Care Participants per 1,000 Population (2006)	Spending per Participant, Weighted Average of Nursing Home and HCBS[a] (2006)	Percentage of Home- and Community-Based Services in Total Long-Term Care		Spending per State Resident (2008)
			Participants (2006)	Spending (2008)	
United States	10.8	$20,451	47%	27%	$220
Alabama	7.7	**$12,912**	26	11	$201
Alaska	13.1	***63,812***	***86***	63	293
Arizona[b]	n/a	n/a	n/a	n/a	n/a
Arkansas	***18.9***	**12,912**	46	21	250
California	13.8	19,261	69	51	210
Colorado	7.0	18,943	48	23	132
Connecticut	15.0	21,853	25	9	392
Delaware	5.8	30,808	27	9	221
District of Columbia	13.0	30,125	44	40	513
Florida	8.7	14,005	27	12	149
Georgia	5.9	21,850	27	19	170
Hawaii	5.6	30,948	31	19	212
Idaho	11.6	18,787	70	39	169
Illinois	9.8	14,063	42	24	151
Indiana	8.3	15,328	8	5	206
Iowa	10.5	15,136	34	16	186
Kansas	11.7	15,647	48	36	200
Kentucky	9.5	17,342	29	8	205
Louisiana	10.3	15,201	28	27	222
Maine	14.1	19,813	53	24	249
Maryland	6.1	27,188	24	12	201
Massachusetts	12.3	25,837	29	21	314
Michigan	11.8	17,684	55	19	183
Minnesota	14.4	21,496	58	51	313

Mississippi	11.9	16,704	34	1	244
Missouri	18.8	13,329	65	30	205
Montana	10.6	20,956	49	28	220
Nebraska	10.2	22,001	37	19	231
Nevada	5.4	21,191	64	35	96
New Hampshire	7.7	29,146	28	15	268
New Jersey	8.7	29,213	38	20	267
New Mexico	10.4	22,995	64	***64***	242
New York	16.1	29,613	34	29	***525***
North Carolina	12.5	19,566	61	41	201
North Dakota	12.5	18,548	28	9	287
Ohio	11.9	21,451	29	18	269
Oklahoma	12.7	14,959	52	29	205
Oregon	11.4	20,720	76	53	184
Pennsylvania	8.8	34,552	23	11	349
Rhode Island	13.0	21,041	22	13	323
South Carolina	6.7	20,051	44	23	145
South Dakota	9.7	15,587	26	8	187
Tennessee	5.8	20,752	**5**	**4**	174
Texas	11.6	13,193	64	33	118
Utah	**3.3**	14,963	30	12	**68**
Vermont	15.5	14,057	41	32	268
Virginia	5.4	21,078	32	30	136
Washington	12.1	19,733	72	59	213
West Virginia	11.8	24,522	47	19	302
Wisconsin	12.4	20,381	50	28	218
Wyoming	8.5	15,806	36	16	155

Sources: Authors' compilation of Burwell, Sredl, and Eiken (2009); Harrington, Carillo, and Blank (2009); and Harrington, Ng, and Watts (2009).
Note: Within columns, minimum values are marked in **bold**; maximum values are ***bolded and italicized***.
n/a = not available.

[a] Per-participant spending is the state average per-participant spending on nursing homes weighted by the national average share of participants in nursing homes (53 percent) plus the state average per-participant spending on HCBS weighted by the national average share of participants in HCBS (47 percent).

[b] Data for Arizona are not available. Medical care for older adults is provided through a managed care program, which includes both acute and long-term care services. Data are not published for these services separately.

Washington, and Oregon), more than two-thirds of people receiving paid long-term care live in their own homes or in community settings. In Tennessee and Indiana, in contrast, fewer than 10 percent of Medicaid long-term care recipients receive home- and community-based services (Howes 2010; Harrington et al. 2009). In Alaska, fully 86 percent of adult long-term care recipients receive HCBS, compared to the national average of 47 percent (Harrington, Ng, and Watts 2009; Harrington et al. 2009).

If tipping the balance toward the use of HCBS has increased the choices and autonomy available to Medicaid consumers, it has also helped slow the growth of per capita costs in states. For example, California and Rhode Island have similar levels of participation in Medicaid-provided long-term care (13.8 per thousand and 13 per thousand, respectively) and of spending per participant ($19,261 and $21,041, respectively), after controlling for differences in the mix between institutional and non-institutional care. Yet because California has a far larger share of people in home care (69 percent of its participants, compared to 22 percent for Rhode Island), it spends far less per state resident on Medicaid long-term care services: $210 compared to Rhode Island's $323.

LONG-TERM CARE FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES In 2007, 328.3 people with intellectual and developmental disabilities for every 100,000 in the U.S. population were getting services—again, with a significant variation across states.[9] Four states (Texas, Georgia, Alabama, and Tennessee) provided services to fewer than 150 per 100,000, while eight (Alaska, California, Iowa, Idaho, Massachusetts, Minnesota, New York, and Vermont) provided services to more than 450 per 100,000 (see table 7.7). On the national level, only 6 percent of those with mental disabilities received paid care through these programs, with state averages ranging from 2 percent in Alabama, Kentucky, Mississippi, Tennessee, and Texas to 20 percent in Idaho. Even after controlling for differences in settings, the average amount that states spent on each participant in 2007 varied enormously, from a low of $28,476 in California to a high of $111,310 in Delaware.

As discussed in chapter 6, great progress has been made in recent years in deinstitutionalizing people with intellectual and development disabilities. As of 2007, only 6 percent—61,000—of the 990,000 beneficiaries of publicly funded services were living in residences with sixteen or more residents, including 38,000 in large state hospitals (down from 228,000 in state hospitals in 1967). But a person's likelihood of remaining in a large institution is still high in certain states. In 2007, 38 percent of people in Mississippi with intellectual and development disabilities were housed in five large state hospitals with 100 to 400 residents each, as were 22 percent of those in Texas and 30 percent in Arkansas. By contrast, seven states have eliminated large institutions entirely in favor of small residential settings and family homes (Prouty, Alba, and Lakin 2008).

State policies also vary enormously in unmet need for home- and community-based care for persons with intellectual and developmental disabilities. As of the end of 2007, residential service capacity for persons who wanted to live outside

TABLE 7.7 / Medicaid Long-Term Services and Supports for Adults with Intellectual and Developmental Disabilities, 2007

	Participants per 100,000 Population	Persons with Mental Disabilities Receiving Services	Spending per Participant (Including Residential and Home and Community-Based Services)	Participants in Family Homes	Participants in Small Residential Settings	Participants in Large Residential Settings	Spending per State Resident
United States	328.3	6%	$55,015	52%	41%	6%	$166
Alabama	140.1	**2**	52,378	49	48	3	67
Alaska	629.2	12	70,252	82	18	**0**	152
Arizona	403.6	9	30,934	84	15	1	113
Arkansas	192.8	3	48,198	29	41	30	156
California	474.4	10	**28,476**	69	28	3	140
Colorado	219.7	5	41,029	37	62	1	94
Connecticut	386.4	9	80,395	57	37	6	380
Delaware	341.5	7	***111,310***	66	30	5	175
District of Columbia	331.5	6	78,660	31	69	**0**	179
Florida	270.9	5	35,733	72	22	6	91
Georgia	126.1	3	36,150	50	41	9	54
Hawaii	257.5	6	42,256	67	33	**0**	124
Idaho	***1016.2***	***20***	50,197	74	23	3	185
Illinois	246.3	6	51,182	35	45	19	134
Indiana	227.5	4	51,968	26	71	3	175
Iowa	458.1	9	38,094	37	51	12	250
Kansas	264.2	5	40,768	34	60	6	164
Kentucky	151.8	**2**	88,333	38	52	10	84
Louisiana	352.4	5	51,656	54	34	13	198
Maine	274.5	4	104,105	9	***90***	1	313

(*Table continues on p. 176.*)

TABLE 7.7 / *Continued*

	Participants per 100,000 Population	Persons with Mental Disabilities Receiving Services	Spending per Participant (Including Residential and Home and Community-Based Services)	Participants in Family Homes	Participants in Small Residential Settings	Participants in Large Residential Settings	Spending per State Resident
Maryland	173.1	4	52,987	25	72	3	132
Massachusetts	485.5	10	71,689	64	33	3	221
Michigan	334.3	6	44,360	49	50	**0**	115
Minnesota	540.2	12	62,837	49	48	3	334
Mississippi	175.5	**2**	65,151	34	27	**38**	132
Missouri	246.3	4	52,495	56	36	8	122
Montana	432.1	8	35,668	56	42	2	123
Nebraska	212.3	5	53,614	**12**	73	15	153
Nevada	158.2	4	55,428	64	34	2	**54**
New Hampshire	171.5	3	44,201	22	77	1	152
New Jersey	424.8	10	88,176	69	20	10	186
New Mexico	167.1	3	69,290	33	67	**0**	177
New York	641.9	13	97,257	64	34	3	**453**
North Carolina	294.6	5	66,811	56	35	9	162
North Dakota	418.7	10	33,890	28	66	6	323

Ohio	341.6	6	61,577	47	42	11	236
Oklahoma	256.1	4	56,100	54	33	13	143
Oregon	299.8	5	40,234	49	50	1	152
Pennsylvania	413.5	8	58,796	***100***	**0**	**0**	214
Rhode Island	281.3	5	80,661	29	70	1	285
South Carolina	395.7	7	51,530	73	21	5	126
South Dakota	378.8	9	37,452	26	69	6	166
Tennessee	146.3	**2**	90,876	42	50	8	153
Texas	**116.5**	**2**	56,810	18	60	22	89
Utah	185.9	4	35,916	39	46	15	87
Vermont	457.4	7	51,020	51	49	0	208
Virginia	214.0	5	71,904	59	32	9	112
Washington	321.9	6	42,279	66	28	6	117
West Virginia	247.7	3	61,097	56	43	1	182
Wisconsin	364.0	8	40,876	30	65	5	162
Wyoming	410.0	8	49,859	35	61	4	239

Sources: Authors' compilation of Prouty et al. (2008) and U.S. Census Bureau (2009b).

Notes: Within columns, minimum values are marked in **bold**; maximum values are ***bolded and italicized***. Participants include some children, all adults, and some older adults; long-term care services for most children with intellectual and development disabilities are covered under Early and Periodic Screening, Diagnosis, and Treatment (EPSDT); some older adults move from ID/DD programs to those aimed at persons over sixty-five when they become eligible. Most children live at home; only 1,600 children were living in large institutions in 2007 (Prouty, Alba, and Lakin 2008); only 6.2 percent of out-of-home placements were children in 2005 (Lakin et al. 2009); children represent only a small percentage of the population in this table.

their family home, either in their own home or in a congregate care setting, would have had to expand by 46 percent nationwide to clear the waiting lists (not shown in table 7.7). In Washington, capacity would have had to expand by only 4 percent, and there were no waiting lists at all in many other states, including New York and Rhode Island. In contrast, Texas, Indiana, and Ohio would all have had to triple capacity to clear their waiting lists (Prouty, Alba, and Lakin 2008). The great volume of complaints against states that have been filed with the U.S. Department of Justice since the Supreme Court's 1999 *Olmstead v. L.C.* decision offers poignant testimony to the inadequacy of home- and community-based services (Ng, Wong, and Harrington 2009).

Just as with long-term care for the elderly and for younger adults with disabilities, per capita costs to the state vary depending on how many people are covered, how adequate the coverage is, and what percentage of the program recipients are living in home- and community-based settings rather than in larger institutions. For example, though Maine and Minnesota each spend just over $300 per state resident on services for people with intellectual and developmental disabilities, Minnesota is able to serve twice as many people because 49 percent of its program participants live in family homes, in contrast to just 9 percent of Maine's.

SUMMARY

Our first conclusion is that money matters. People at all income levels are served by various care policies in the United States, but the adequacy of the supports available to those in need of care and to their families varies dramatically depending on their household income. The affluent turn to private markets and generally have access to higher-quality care services, have more options, and are able to preserve more of their independence and autonomy. The poor linger on waiting lists until rationed care becomes available or rely on means-tested public programs for care that is often meager or low-quality and more likely than privately financed care to be institutional. Middle-income families frequently face the most limited options, since they lack the resources to buy private care yet earn too much to qualify for means-tested public programs. If they cannot afford the long-term supports and services that they need, they must spend themselves and their immediate family members into (income and asset) poverty in order to qualify for Medicaid. And when they do, their choice of services in many states is limited to nursing homes.

One exception to the rule that better services and more autonomy can be purchased in the private market is Medicaid's EPSDT program, which requires states to provide an exceptionally broad range of services to low-income children in order to ensure that they all receive needed health care services and that those who have developmental delays or other disabilities get early intervention and treatment to increase their chances of succeeding in school and in later life. Services are delivered in child care centers and in prekindergarten and elementary and secondary schools, greatly increasing the likelihood that they will reach their targets. Because EPSDT provides for preventive care as well as treatment, and for both acute and long-term care needs, it is perhaps the closest that we have to a model of adequate health care, but it is not available to middle- and higher-income children. The private medical insurance system that these children and their families are left to rely on is not designed to provide the diagnosis and early treatment needed by children with developmental delays or disabilities. Recognizing this fact, a few states have expanded eligibility for EPSDT into the middle class, setting higher income eligibility thresholds or disregarding family income that would be spent on care services.

Our second conclusion is that geography matters. Policies that shape the adequacy of ECEC, family leave, foster care, and services and supports for children, frail elders, and adults with disabilities vary sharply across the fifty states. Most of the care policies under consideration are financed through federal-state partnerships, or at the state level. Although federal support is critical for these programs, states nevertheless spend about one-third of their budgets on care services, including ECEC, early intervention and special education services, comprehensive medical services for children with developmental delays or disabilities, foster care, and long-term care supports and services for adults who need personal assistance. A significant portion of the federal support for various care services comes through nondedicated funding streams such as TANF and the Social Services Block Grant. As a consequence, ECEC, foster care, and some services for the elderly and younger adults with disabilities compete for limited resources at the state level. State supplemental funding for these services competes with funding for schools and infrastructure.

Many states try to limit demand for care services, using a well-worn set of tools. They may set caps on expenditures and enrollment, maintain long waiting lists even for entitlements, or set high copayments to discourage service use. Some states offer a limited array of relatively appealing services, while others set unusually low income and asset thresholds for eligibility. Some observed differences in policy outcomes are certainly attributable to factors other than policy variation, such as demographic and workforce differences across states. However, dramatic cross-state variations in policy rules also play a significant role in producing marked geographic disparities in the receipt of care services in the United States.

Despite the temptation for all states to cut costs by limiting services, some states are relatively generous in providing support for care in one or more policy areas. These states may in some cases provide significantly more generous benefits than the national average, may have substantially higher participation rates, or may make more choices available to families in terms of the types and settings of services supported. For low-income parents of young children in Vermont, for example, the likelihood of receiving child care assistance subsidies or of having one's child enrolled in Head Start or a publicly supported prekindergarten program is twice the national average. Moreover, Vermont has expanded unpaid family leave, allowing workers in small firms to take job-protected leaves and extending the definition of family members to include civil union partners for purposes of caring leaves. Foster care monthly maintenance payments in Vermont are among the highest in the country. In terms of providing health care benefits for children, Vermont is the only state that sets the income threshold for EPSDT eligibility at the maximum allowable 300 percent of the federal poverty line ($54,930 for a family of three in 2010) for all children younger than nineteen. Vermont is also relatively generous in its policies with regard to serving adults with disabilities and older adults; the state is in the top tier in terms of rates of receipt of publicly funded long-term supports and services among these two populations.

As might be expected, this sort of policy generosity with regard to care is most common in northeastern and Pacific coast states, but is not restricted to them. In addition to the "usual suspects," such as New York, Washington, California, and Massachusetts, other states, including Alaska, Minnesota, and Oklahoma, are among the states that are particularly generous in many (although not all) of the care policy areas discussed in this volume. Some states simply exhibit generosity in terms of higher expenditures per recipient or policies that provide expanded access to services, but policy innovation also plays a significant role. Many of these states are particularly innovative in the design and implementation of their programs, and many offer a range of options for families, such as encouraging kinship care in the foster care sphere or providing access to long-term care choices through home- and community-based services.

On the other hand, another set of states—including mostly (but not only) southern and western states such as Alabama, Nevada, Tennessee, and Utah—are generally problematic places to live with respect to the availability of supports for care of children, the disabled, and the frail elderly. For working parents who need help obtaining child care, families of children with special health care needs, those responsible for caring for an ill family member, and those in need of long-term supports and services, these states, among others, provide relatively meager benefits. These less generous states consistently fall into the bottom tier in take-up and spending in most of the care support programs discussed here and, unsurprisingly, also tend to have care policies that are less expansive and less innovative with regard to eligibility, access, and choice.

Although there are clearly some states that are consistently generous in their care policies and some that are consistently less generous, perhaps more notable than the policy variation *between* states is the policy variation *within* states. For example, some states are particularly generous in some of the care policy areas outlined earlier but particularly restrictive in others. These disconnects between policy areas belie the straightforward conclusion that some states are simply more generous with regard to care supports and others simply less so. Some states are particularly generous in one policy area; Georgia, for example, is a leading state in implementing universal prekindergarten but is less generous in other care policy areas. Some states, such as Maryland and Texas, seem to prioritize the needs of children and parents, while providing relatively meager support to the elderly and disabled. Others, such as Maine and Oregon, seem to have the reverse priorities. In some states, there is no consistent policy with regard to children as opposed to the elderly and disabled; for example, Florida is one of the most generous states in terms of care policy for the disabled and foster children, but one of the least generous in terms of care of the frail elderly and support for child care. Moreover, there is often a disconnect within policy areas; for example, spending per beneficiary may be high, but the take-up of benefits among eligible residents may be low. To the extent that benefits and take-up are determined by state policies and administration, these disconnected policy features may indicate a lack of consistency in state policy design and implementation.

The strengths and limitations of our care policies provide clues to what a better care system would entail. Although our country's federalism provides the opportunity to learn from diverse types of policies, the states do not always move quickly to build on the experiences of their more successful neighbors. Residents of many states remain vulnerable to significant shortfalls in care provision, and current policies exert an uneven impact across lines of both income and geography, with unfortunate consequences for caregivers as well as care recipients. Improving access to care and the quality of care will require national policy reform.

NOTES

1. As in chapter 6, we use the term "early childhood education and care" to encompass two types of programs: child care programs, which are primarily intended to provide substitutes for parental care, and early education programs, such as Head Start and prekindergarten programs, which have an explicit educational purpose.
2. In their study of state preschool programs, Barnett et al. (2009) reported that as of 2008–2009, thirty-eight states funded public prekindergarten programs separate from special education services and Head Start. Of these, thirty-two states imposed income requirements. Although the income requirement is set at the federal poverty line in some states, more typically it is set higher, often between 185 and 300 percent of the federal poverty line.
3. This estimate of the number of children in foster care differs modestly from the estimate reported in chapter 6. This may be partly because the two estimates come from different sources, but the more important factor is probably the difference in time periods, as the small decline between 2006 and 2008 is consistent with widespread reports of declining foster care caseloads.
4. There are some regional patterns. Five of the six states in the New England census division were in the top two quintiles. No mountain or west-north-central states were in the top quintile. Seven of the ten states in the lowest quintile were in the west region, and five were in the mountain division of the west region (Kenney et al. 2010).
5. There are also fewer eligible children in states with higher income levels and lower poverty rates.
6. Using pooled data from the 2002 to 2005 Medical Expenditure Panel Survey, Genevieve Kenney, Joel Ruhter, and Thomas Seldon (2009) found that annual expenditures on children in the highest spending decile of EPSDT/CHIP enrollees was more than seven times that of mean spending, and thirty-five times that of median spending on children. Sixty-six percent of children in the top decile had special health care needs, and 68 percent had chronic conditions, roughly three times the rate of the rest of the EPSDT/CHIP enrollees. The top spending decile of children accounted for 72 percent of all EPSDT/CHIP spending.

7. The U.S. Department of Education does not maintain data that can be used to compare total spending on special education across states. However, Parrish (2010) has developed a method for estimating expenditures based on employment costs, which he argues represent about 85 percent of total costs (Parrish, personal communication, November 3, 2010). Using his index of relative expenditures across states, we have estimated spending per capita in each state.
8. The Cash and Counseling program, jointly sponsored by the Robert Wood Johnson Foundation, the Assistant Secretary for Policy and Evaluation and the Administration on Aging, made initial grants to seventeen states over a ten-year period. Many of these states have continued to support the program.
9. Most discussions of disability policy for intellectual and developmental disabilities report coverage as number of participants per 100,000 population, while most discussions of long-term care services for aged adults and adults with disabilities report coverage as number of participants per 1,000 population.