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The Reinvention of Caregiving

Given the economic changes that have taken place in family structure, one of the main functions of the family—nurturance and caregiving—is under siege. Smaller families with fewer generations present, longer life expectancies, and more mothers in the paid labor force have all resulted in a dearth of caregivers for children, older persons, and anyone with a short-term illness or a long-term disability. American families have adapted to this change in two ways. First, specialization has occurred so that there are different kinds of care for different ages and different needs: nursing homes for the elderly, childcare for preschoolers, and accommodations for persons with one type of disability or another. The second major trend is toward universalization of process and coverage. The earliest supplements to family caregiving were for poor people, old people, and those with handicapping conditions. Gradually over the course of more than a century, the bases for entitlement have become much more inclusive.

It is not as though American society has let these changes come about with no adaptive response. Caregiving has been rationalized so as to serve a greater number of children, elders, or ill people. But this kind of care by professionals such as teachers, doctors, nurses, orderlies, and childcare workers takes place outside the family in institutional settings. For example, the movement from a sick bed at home to a bed in the hospital has saved lives. Yet at the same time, since the 1950s, it has become ever clearer that rationalized and bureaucratized care can result in assembly-line treatment or warehousing of frail elders in nursing homes or of severely disabled persons in the back wards of state-run mental hospitals. Moreover, paid care for dependents in a specialized setting costs more than unpaid caregiving by family members at home.

For more than a generation, since the Kennedy family's crusade in the 1960s and 1970s to de-institutionalize care of persons with cognitive disabilities, advocates have argued that it is more effective, economical, and humane to provide care in the least restrictive setting. In addition, rather than segregating categories of individuals by age or type or severity of disability, the new paradigm of caregiving calls for treating aging and development as a lifelong process in which earlier experiences shape and help to determine capacity later on. This perspective leads to a focus on prevention and individualized care in naturalistic settings rather than treatment that is delayed until a person enters a specialized institution.

These general trends toward treating caregiving as a normal and natural lifelong need and a lifelong process can be found in three major domains of caregiving: elder care, childcare, and family health care, as well as care for persons with mental or physical disabilities. Up to now, these programs have been seen as separate entities oriented to different categories of persons who need a variety of different kinds of services. The central theme of this chapter, however, is that these separate streams of caregiving are all related to each other as a major part of family policy because they all have to do with lifelong development and the family's central caregiving function from birth to death. When the family is unable to give the care that is needed, it is outside help from charitable organizations or government-sponsored services that step in to supplement care from the family. Family policy encompasses both the facilitation of care by the family and the provision of care outside the family.

Elder care became an issue as people lived longer and urbanization and industrialization took away their traditional pattern of living with their children. Charitable organizations and town governments responded to the growing elder population by providing relief or a place to live. In the 1935 Social Security Act, Old Age Assistance was made available to needy elders, and the institution of Medicaid in the 1960s provided financial support for care in nursing homes for those at or near the poverty line.

Services for children and youth also grew out of charitable efforts to help widows and orphans. Child support and mothers' pensions were regularized in Aid to Dependent Children in the 1935 Social Security Act. Other programs for children and youth eventually included childcare, preschool education, child welfare, child protection against abuse and neglect, foster care programs, and the juvenile justice system.

Family-related health and disability services are one of the most active and growing areas of family policy. Beginning with the work of the Children's Bureau, maternal and child health programs grew throughout the 1920s under the provisions of the Sheppard-Towner Act, and then following defeat of its reauthorization emerged again in programs established in the

1930s. More recent additions include the Women, Infants, and Children (WIC) program and the Children's Health Insurance Program (CHIP). The Affordable Care Act of 2010 is a major attempt to advance universal health insurance coverage for families. Also related to health care are extensive programs in mental health and services for persons with disabilities. One of the most vibrant developments in the world of caregiving is the disability rights movement, which has worked for greater autonomy and control by the persons receiving care.

One important by-product of the past rationalization and institutionalization of caregiving outside the family is the development of a *reproductive* labor force (which is "reproductive" in the sense that caregivers are helping to sustain life rather than produce material goods or services). The top tier of this labor force includes a growing cadre of professionals such as medical personnel, childcare workers, teachers, or social workers. The bottom tier, however, is low paid, and of largely minority status—a group who are often insecure in their jobs despite their indispensable work as practical nurses, food workers, or janitorial staff. An important question for improving caregiving both inside and outside the home is how the reproductive workforce is organized, how caregivers perform their work, what rewards they receive for doing a good job, and how they interact with family members. Critics point out that improvement of caregiving will not happen until the organization of care becomes more person centered than rule driven. Rank-and-file workers in caregiving must also be accorded due respect, dignity, adequate pay, job security, and opportunities to improve their qualifications.

This chapter first examines how the modern care system has developed in the specialized domains of elder care, childcare, health care, and disabilities. The chapter concludes with a review of trends in the caregiving labor force.

Trends in Elder Care

Homes for elders got their start during the nineteenth century as poor farms or poorhouses, which were the charitable solution to care for older people when they had no family members to whom they could turn for housing or other forms of assistance. For those veterans who had served in the Civil War or Spanish-American War there were Soldiers' and Sailors' Homes in cities and towns throughout the country that eventually took in veterans of later wars as well. Such institutions were a new development because for most of human history, elders did not live so long. Old people who did survive were generally treated with respect and provided a place to live where they could contribute some help to the family and partake of its benefits. With improvement in

health conditions, the demographic pyramid became wider at the top as the population of elders grew larger. At the same time, economic modernization led to the downsizing of the family and its specialization in consumption rather than production. Together, these demographic and economic trends brought about a major change in the living situation of older people.

In her cross-cultural studies of aging based on 1960s data, Shanas (1973) found that in the United States, as in other Western countries, parents preferred to live independently and avoid placing a burden on their children. Yet at the same time, American elders generally lived within a short distance of children or another relative and could call on them if in need of help. This picture contrasted sharply with that in many Asian countries where elders typically expected to live with their children (Giele 1982b). The Western pattern of separate living arrangements had come about as a result of economic modernization and urbanization. No longer in control of a family farm or business, seniors could not command rights to live with or be cared for by their children (Cowgill and Holmes 1972). Yet, as late as the 1940s some states still tried to enforce filial responsibility laws that required adult children to support their parents if they needed public assistance (Schorr 1961).

The increasing population of older people and their new vulnerability helped to stimulate the growth of several new social institutions to provide for their welfare such as pension systems, new types of living arrangements, and provision for medical and long-term care. To understand the evolution of caregiving for older persons, it is necessary to examine three trends that are intertwined: demographic change, invention of retirement and pension systems, and the expansion of social services and home care.

Growth of the Elder Population

Just as infant mortality dropped dramatically with the advent of modern medicine, so also life expectancy improved, and this allowed many more individuals to survive into adulthood and old age. Between 1900 and 1950 the life expectancy of both sexes increased on average by about 20 years, from approximately age 50 in 1900 to age 70 in 1950 (Kinsella 1992). By 2015, life expectancy for males is projected to rise to 76 for men and 81 for women. In 1900, only 4 percent of the population was 65 years old or over, but that proportion had risen to 11 percent by 1985 and is projected to reach over 14 percent by 2015 (U.S. Census Bureau 2009b).

So many more people living longer means that illnesses cured at younger ages result not only in longer life but also more people with chronic disabilities or age-related diseases such as stroke, heart failure, loss of hearing or vision, arthritis, and neurological diseases like Alzheimer's and Parkinson's.

The growing need for care of older people with chronic health problems imposes a significant burden on society and on families to provide care. Yet at the same time that more people are living longer and have a need for more care, families have become smaller and less self-sufficient, and women who have been the traditional family caregivers are less likely to be at home full time. A recent study by the Urban Institute estimates that in the year 2000 slightly fewer disabled older adults (22 percent) were receiving paid help (which averaged 163 hours per month) while slightly more (28 percent) were getting unpaid help from their families. If family size continues to decline and the great majority of adult women continue to be employed, it is likely that the balance in the future will shift to slightly more reliance on *paid* than unpaid help (R. Johnson, Toohey, and Wiener 2007).

These demographic changes have helped to bring about a reorientation in the field of aging research over the last 40 years. An important breakthrough was the realization that the aging process varies greatly by age cohort because each group grows up in a somewhat different set of economic and cultural conditions. Concern has shifted from a focus on post-retirement elder needs and services to consideration for the whole life span and how the aging process can be improved.

Differences among age cohorts. It was once thought that older people declined intellectually as they aged. But when psychologists tested people using longitudinal methods (comparing people of specific age groups over time), it turned out that people born earlier in the century had less education and therefore scored lower on the cognitive tests (Schaie 1977). Economists, sociologists, and demographers made similar discoveries when they compared the life patterns and work histories of different age groups (Ryder 1965). Wives born in the 1880s had only 18 years between the birth of their last child and their own or their spouse's death, whereas a woman born in the 1950s had about 30 such "child free" years (Giele 1978:147).

The cohort perspective is also relevant to demographic projections for the future. For example, Asian, African American, and Hispanic populations predominate in younger cohorts and white non-Hispanics in older cohorts. Due to the higher fertility rates of these ethnic groups, half of all Americans will be from these minority groups by 2050 (J. Angel and Angel 2006). These family-based demographic changes will have major implications for social policy and social provision in the future. Much will depend on the poverty levels, education, and health of these groups and whether the nation will be able to provide economic security and health and social services to its older population. It is in the national interest for families to be able to promote good health over the life span, from birth to death.

Healthy aging. If different birth cohorts have quite different life patterns depending on the economic conditions and cultural climate in which they were born and grew up, the quality of old age also varies with differences in life history. How does one define successful aging and the key factors that contribute to quality of life and subjective well-being?

Baltes and Baltes (1990), in their book on *Successful Aging: Perspectives from the Behavioral Sciences,* used the life course perspective to suggest three characteristics of older people who age most successfully. In contrast with *normal* aging that always involves some loss of capacity and *pathological* aging due to disease, *optimal* aging occurs when individuals maintain a high level of performance by *selecting* a few satisfying activities on which to focus, *optimizing* performance by practice and hard work, and *compensating* for age-related losses by using technical aids or performance strategies that minimize the loss (Baltes and Baltes 1990:26).

More recently, the concept of successful aging has been debated in terms of whether it varies with socioeconomic and cultural context. Based on a ten-year study by the MacArthur Foundation, Rowe and Kahn (1998) conclude that there are three main components of successful aging: avoiding disease and disability, maintaining a high level of physical and cognitive functioning, and engagement with life. Isolation and a lack of social ties is a powerful risk factor for poor health. Conversely, social and emotional supports help to diminish some of the health-related losses of aging. The key source of such social support is, of course, family and friends. When a spouse dies or friends move away, it is thus important to find new forms of social engagement and develop "convoys of social support" that will compensate for these losses while staving off poor health and promoting healthy aging (Rowe and Kahn 1998:161).

One critique of Rowe and Kahn's synthesis is that it puts undue emphasis on individual agency and control while failing to take into account working-class perspectives that may be more accepting of structural limitations and objective conditions that work against an independent lifestyle (Hendricks and Hatch 2006). Likewise, George (2006) suggests that different definitions of "successful aging" can be encompassed within a broader concept of "subjective well-being." Thus, the person with a disability may still feel that she has a high quality of life.

The new interdisciplinary program on Life Span Development and Healthy Aging at Brandeis University (2010) sidesteps the debate on how to define successful aging by listing five pillars of healthy aging that apply to everyone regardless of social class, ethnicity, gender, or health limitations. To age healthily and successfully, a person should attend to these five factors: (1) have a sense of control, (2) receive social support, (3) reduce stress and

anxiety, (4) exercise regularly, and (5) undertake cognitively simulating tasks. The family context and family caregivers can facilitate all five of these dimensions, but especially the provision of social support.

Retirement Security

In stark contrast to contemporary concerns about successful aging, the main worry of older people over the past two centuries has been economic insecurity and poverty. Great improvement occurred as poor houses were replaced by a variety of pension schemes that enabled older men and women to live independently and with dignity. The landmark Social Security Act of 1935 laid the groundwork for a universal safety net in the retirement years. The program has grown steadily from its inception in 1935. In 1940, only 220,000 persons were receiving benefits, but the program has been expanded to include Medicare, Medicaid, and social services as shown in Table 4.1. Today more than 50 million Americans currently receive a Social Security benefit, and more than 90 percent of all workers are in jobs covered by Social Security (DeWitt 2009).

Remarkably, the 1935 Social Security Act was passed in a relatively short time (Schulz and Binstock 2008) and has since been expanded to cover groups

Table 4.1   Major Federal Programs To Help Elders Since 1935

Enabling Legislation	Year	Provisions
Social Security Act (SSA)	1935	Persons over 65 receive income from contributions based on earnings in covered occupations
Medicare and Medicaid (Titles XVIII and XIX of SSA)	1965	Medicare available to persons 65 and over on basis of past earnings. Medicaid for those with low income and assets
Older Americans Act	1965	Area Agencies on Aging to provide services for all 65 years old and over, especially poor, rural, and minority elders
Supplemental Security Income (SSI) (Title XVI of SSA)	1972	Consolidation of categorical state programs for Old Age Assistance, blind persons, etc. to provide income to those without sufficient income from past earnings
Social Services Block Grant (Title XX of SSA)	1974	Funding for states to provide Social Services to promote self-sufficiency, prevent abuse or neglect, and prevent or reduce inappropriate institutionalization

that had earlier been excluded such as self-employed persons and household and agricultural workers. In 1965, Medicare and Medicaid were added as Titles XVIII and XIX of the Social Security Act. In 1974, the Supplemental Security Income program and Title XX, the Social Services block grant, brought a congeries of state programs for needy elders, blind persons, and disabled individuals under the federal Social Security umbrella (DeWitt 2009).

Social Services and Long-Term Care

Even if an older person's retirement income is entirely adequate, there is still a question of financial adequacy if one falls and breaks a hip or develops a degenerative neurological disease such as Parkinson's or Alzheimer's. Adequate income has to be somehow transformed into reliable caregiving that is both compassionate and competent. The provision of such services has been a special challenge for the United States because, as explained by Kamerman and Kahn (1976:377), "U.S. health programs are essentially funding devices, not provision for service delivery." Yet as President Nixon said at the 1971 White House Conference on Aging, ". . . the greatest need is to help all older Americans to go on living in their own homes" (Kamerman and Kahn 1976:315), and such a need can only be met by providing services in the home or in a retirement community rather than in a specialized institution that is focused primarily on health care.

Over the past four and a half decades since the passage of Medicare and Medicaid, a series of legislative and private initiatives has produced a wide array of services to older adults that are delivered to the home. The Older Americans Act of 1965 established Area Agencies on Aging and services for care management, home assessment, and nursing help. The Social Security Amendments of 1965 that established Medicare and Medicaid supported health care for those over 65. By 1970, Medicare covered 97 percent of older Americans, which represented a doubling of the population who had formerly been covered by private insurance (Moon 2006). In 1973, the Supplemental Security Income legislation amended the Social Security Act to cover all those previously covered categorical programs for Old Age Assistance and for blind and disabled persons that had been under the control of the states. The 1974 Title XX of the Social Security Act, known as the Social Services block grant, provided for essential social services such as homemakers and meal preparation for needy elderly. Although that legislation provides a commendable array of services (housework, health aides, home management, personal care, consumer education, financial counseling), only 6 percent of the funds were used for elders in 2000, the remainder being used for younger age groups (Gelfand 2006). In 1982 the Medicare program

authorized nursing services, medical social services, and counseling and bereavement support to all Medicare and Medicaid clients (Csikai 2009). In addition to the government-funded social services to elders, there has been phenomenal growth in nonprofit and commercial agencies for delivery of home services, estimated in 2003 to be 7,000 agencies that were certified to receive Medicare and Medicaid reimbursements and another 3,000 to 6,000 that were not. Typically these agencies provide health aides who do chores, light housekeeping, food preparation, laundry, and where required, also help with bathing, exercise, and transfer from bed to chair (Adams 2009).

The result of the growth in provision of such services is that there is a strong grassroots feeling that more long-term care should be provided in the community rather than in institutions. There are several advantages of home-based care for the well-being of the older person. Face-to-face interactions in familiar settings are associated with better cognitive functioning as well as protection from the onset of disability (Moren-Cross and Lin 2006). Other benefits of home services include greater comfort and security as a result of being in familiar surroundings. Moreover, from the standpoint of a caregiver or caseworker, seeing the person at home gives a better understanding of the problem and how to provide help (Adams 2009). There are now programs in some states to use Medicaid waivers to divert payments for care in a nursing home to payments for foster care in a family setting. Another important development is end-of-life palliative care provided by hospice organizations, whose services are paid for by Medicare and Medicaid once a patient has waived the option of future curative treatment (Csikai 2009). Finally, senior centers—partially funded under the Older Americans Act—in some cases provide telephone reassurance and friendly visiting that support community volunteers and the general effort of helping persons remain in their homes (Gelfand 2006).

The spectrum of alternatives for long-term care of seniors is now much broader than in 1965 when the Older Americans Act and Medicare were instituted. The range runs from skilled nursing facilities to assisted living; full-service retirement communities for independent living; congregate housing; and local, state, and federally funded low-income housing projects for seniors (Bookman 2008). The newest development is found in the "village" movement which is modeled on the Beacon Hill Village of Boston (2010). There are now roughly 60 villages around the country from Boston and Washington, DC, to suburbs of Chicago, and Palo Alto, California, that recently formed a network for sharing information and ideas (Village to Village Network 2010). Typically, for a membership fee of $500 to $1,000 per household per year, the village provides an array of services including rides to the doctor, assistance with grocery shopping, friendly visits, and access to

vetted fee-for-service providers of home maintenance and home health care, and a variety of opportunities for exercise and social activities that range from bridge games to attending lectures and concerts.

Services to Children and Youth

Just as changes in the number of elders helped to bring about new policies toward aging, so also the modern situation of children has been accompanied by a new realization that their health and future productivity affects the well-being of the entire nation. Declining infant death and family size have led to greater relative investment in every single child (Ariès 1962; Zelizer 1985). Early childhood education has become more important, and young people are encouraged to extend their years in school. Child policy has historically focused on basic welfare (food, shelter, protection) and education, health, and nutrition. Increasingly there is concern about the early years of learning, early brain development, and the capacity to learn, all of which are important for future productivity. A great deal of attention is now directed to the long-term destructive effects of child poverty and the need to provide good early childcare in order to promote optimum growth (Shonkoff and Phillips 2000). Nobel Prize winner James Heckman (2006) points out that families are the major contributors to inequality in social and economic life. This disparity can be remedied by an enriched early childcare environment, and the returns in improved outcomes for disadvantaged children are much higher with early than late interventions.

Policies and programs for children and youth first took root with modernization and the decline of agriculture and rural society. Widows without a husband needed some alternate means of support. Young children without older siblings to watch over them needed care while their mothers worked. Older children with no gainful employment during adolescence could get into trouble. Some children had no living parents or relatives to care for them. Gradually during the late 19th and early 20th centuries, a variety of charitable and public institutions began to address child poverty, day care, child protection, and child health. New programs appeared such as mothers' pensions, day nurseries for childcare, orphanages, and health services for mothers and children. Eligibility for these programs was limited to children at risk of poverty, abuse and neglect, poor health, and lags in development. Much of the reform effort over the past 50 years has been to create more universal programs that cover all children regardless of dire need or low income. Together these policies for child welfare constitute what many early leaders in the field have thought of as the core of "family policy" (Kamerman 1995; Steiner 1981).

Child Support and Mothers' Pensions

Between 1890 and 1920 concerns for child welfare tended to fall into two different camps—one that sought mothers' pensions to keep mothers at home and the other that sought childcare for working mothers. Mothers' pensions were supported by the National Congress of Mothers (later the Parents' and Teachers' Association) along with the Children's Bureau who threw their support behind the "naturalist" idea that mothers' place was in the home. They believed that in case of need or the absence of the breadwinner, the state should pay the mother sufficient income to support her family without going on welfare. The 1909 White House Conference on Children led to a full-fledged campaign for mother's pensions (Sklar 1993; Skocpol 1992). This approach prevailed until passage of the Social Security Act in 1935 and eventually resulted in the creation of the program for Aid to Dependent Children (ADC and later AFDC), which at that time went mainly to widows and their children (Koven and Michel 1993).

The ascendance of child support via mothers' pensions displaced and slowed the growth of the fledgling childcare system that had been started in settlements like Hull House. Yet at the same time, the emphasis on mothers' pensions sowed the seeds of welfare reform in the 1980s and 1990s by protecting the traditional homemaker role even in the face of the significant rise in *married* mothers' labor force participation (Mead 1996). The major reforms in childcare legislation since 1970 reveal the continuing strain between the traditional and progressive views of motherhood—that mothers should stay at home to care for their children or that they can help to support the family if they are given sufficient assistance with childcare.

In the early 1970s, Senator Daniel Patrick Moynihan's Family Assistance Plan (FAP) provided income support for families with fathers who were unemployed as well as for lone mothers. Zigler and Gilman (1996) suggest that President Nixon supported FAP instead of comprehensive childcare legislation because it fit better with the conservative view that mothers should be homemakers rather than breadwinners.

But the inexorable rise in married women's labor force participation and in the number of mothers with young children who were working outside the home raised increasing doubts about the sustainability of paying mothers to stay at home to care for their children. During the late 1970s and early 1980s there was growing demand for stronger regulations to enforce child support obligations of absent fathers. By garnishing their wages and pursuing deadbeat parents across state lines, the AFDC program changed expectations about the support obligations of the absent parent and was also able to recoup some of its costs (Garfinkel, McLanahan, and Robins 1994). Even more radical was

the change brought about by the Republican majority in the 1994 elections led by Newt Gingrich and the "Contract with America." The steady rise in non-marital births suggested to some, like Charles Murray (1984), that income support for AFDC families was a perverse incentive to have children outside of marriage and thereby rely on childbearing and dependency in order to qualify for welfare payments. The critics succeeded in getting welfare reform that imposed a strict time limit of no more than five years' reliance on financial support along with a requirement of the mother to seek job training and be ready to take employment. With this legislation the old AFDC program was replaced by Transitional Assistance for Needy Families (TANF).

Childcare and Preschool Education

Running parallel to efforts to fight poverty and provide poor mothers and children with income support, the other main strategy for putting a safety net under poor children has been to help their mothers take employment. While mothers work, children can be kept clean, well fed, and well cared for. In the earliest day nurseries, set up by settlement houses and other charitable organizations at the end of the nineteenth century, there was often an assimilation agenda to help immigrants and their children learn American standards and customs (S. Rothman 1978). The National Federation of Day Nurseries, which was founded in 1898, had a membership of 600 participating programs 10 years later (Michel 1993).

However, because child support payments were the dominant means of helping poor mothers to care for their children by staying at home, the childcare movement had little visibility until the 1960s and 1970s when more mothers of young children entered or stayed in the labor force. One brief and remarkable exception to the relative absence of organized childcare outside the home occurred during World War II with the passage of the Lanham Act. Companies like the Kaiser Industries in Seattle that produced warships employed many women workers with young children. To accommodate these mothers, beautiful nurseries and childcare centers were established near the Kaiser plants. At the close of the working day, mothers could pick up their children along with a hot meal to take home for dinner (Michel 1999:256). After the war these centers were dismantled as men came home from the battlefield and women workers were demobilized to return to homemaking. But in the 1970s and 1980s, with the rising presence of educated women in the labor force, new efforts to offer nursery schools and infant daycare began to surface. Women faculty and staff members at universities like Brandeis and Harvard organized cooperatives to care for

their children. Nonprofit nursery schools were set up in churches. By 1985, commercial franchises like Kinder-Care had 1,040 centers serving 100,000 children of mostly working parents (Michel 1999:256). Hayes et al. (1990:29) reported the remarkable statistic that during the 1980s only 8 percent of children under 5 were entirely in the care of their employed mother while 22 percent were in family day care, 23 percent were in center-based care, and 37 percent were in some form of home-based care by a father or other relative.

Concurrent with the rise of these practical solutions to the childcare problem were legislative efforts to guarantee public support. The successful Perry Preschool Project in Michigan that helped poor children escape poverty, as well as the creation of Head Start in 1965, suggested the positive gains to be realized from early childhood education. The 1970 White House Conference on Children called for a comprehensive system that would stem the rise of runaways and "latchkey children." Congress responded in 1971 by passing the Comprehensive Child Care Development Act, which would have set up a network of publicly supported preschool centers throughout the country. But President Nixon vetoed the act with a message that America should not adopt a Soviet-style socialist system and that children were best cared for in their own homes. Zigler and Gilman (1996) explain this fateful reversal by the politics of the period in which conservatives argued that such a public system could undermine the traditional American family. In addition, Senator Moynihan's Family Assistance Plan for poor families had greater appeal to those who opposed the public provision of preschool childcare.

Given the defeat of the 1971 legislation, despite the steady growth in mothers' labor force activity as well as use of child care, government has had to respond in some way, even though in piecemeal fashion. In 1990 the Child Care and Development Block Grant provided less than half as much for federal subsidies of childcare as the failed 1971 Comprehensive Child Care Development Act that President Nixon vetoed. Although the Block Grant provided earned income tax credits (EITC) for working parents to deduct costs of childcare from their taxable income, the resources available were in the expert opinion of Zigler and Gilman (1996) far too little.

More recently, roughly 90 percent of preschool-age children with working mothers are in some form of regular childcare, as compared with about one-third of children whose mothers are not employed. The costs of childcare have averaged about 6–7 percent of a family's income for the past 20 years, and only about 10 percent of families received help from any source in covering these costs.

Child Welfare and Child Protection

In addition to child support and childcare, the field known as child welfare also includes protection from abuse, neglect, abandonment, and delinquency. The protective aspects of child welfare have continued to expand since the nineteenth century charitable organizations and Children's Aid Societies began by finding homes for orphans. The current emphasis in child welfare is on family preservation and keeping children at risk of neglect, abuse, or delinquent behavior in their homes whenever possible. Child welfare policy today is based on the principle ". . . that the home is the best place for children to grow, that the state does not make a good parent, and that family systems can change and grow as learning communities" (Lewandowski and Briar-Lawson 2009a:135).

Foster care and in-home services. How to realize this principle of protecting children while preserving the family has changed quite markedly since the Social Security Act of 1935. From 1935 to the 1970s through Title IV-A and Title IV-B, children and their families were kept together and provided services and financial assistance under AFDC. In those situations where the child was at risk of maltreatment, or the family was unable to cope, children were placed out of the home in institutions or in foster care, or were put up for adoption.

In the 1970s the family preservation movement began to change professional views on the best methods of child protection. Rather than placing abused or neglected children in foster care or institutions, the family preservation movement raised the possibility that these children could do better growing up in the care of their own families with services provided in their homes. Title IV-E of the Social Security Act established Permanency Planning in 1980 to help find family-like settings for foster children. Dobelstein (2009), a social policy analyst of the Social Security Act, however, sharply criticizes the family preservation idea; he argues that the 1979 White House Conference on Families displaced the traditional White House Conference on Children and thereby caused a wrong turn in child welfare policy because it shifted the focus from children to families. Nevertheless, the prevailing view is that long-term change is only possible through working with the whole family as a system. Homebuilders of Washington State has developed intensive services for families accused of child abuse and is able within three to four weeks of intensive work to see enough improvement to prevent out-of-home placement of the child (Lewandowski and Briar-Lawson 2009a).

The Social Security Act of 1935 has been gradually amended to discharge child welfare functions somewhat differently now from in the past. Over the

course of recent decades specific laws have been enacted to address child abuse and treatment; others, to support adoption and family preservation; and still others, to change the treatment of juvenile offenders (as shown in Table 4.2).

In 2006, 3.6 million children received investigation or assessment for abuse or neglect, and one-quarter of them were identified as victims of maltreatment. Almost two-thirds of these cases (64 percent) were cases of *neglect*, a category that is known to be clearly tied to poverty. Despite the emphasis

Table 4.2   Major Federal Programs for Children Since 1935

Enabling Legislation	Year	Provisions
Social Security Act (SSA) Title IV-A Aid to Dependent Children (ADC). Became AFDC in 1959	1935 1959	Income support primarily for widows and their children. Later more qualifying families were headed by single parents and divorced mothers
Foster Care (Title IV-B of SSA)	1935	Support for foster care, out-of-home placement
Lanham Act Public Law 76-849	1942	Provided federal funding for states to pay for childcare services for working mothers
Head Start (updated by the Head Start Act of 1981)	1965	Provides comprehensive education, health, nutrition, and parent involvement services to low-income children and their families
Juvenile Delinquency and Protection Act	1974	Reforms in juvenile justice, due process; focus on treatment more than punishment
Child Abuse Prevention and Treatment Act (CAPTA)	1974	Funding to states in support of prevention, assessment, investigation, prosecution, and treatment of abuse and neglect
Child Support Enforcement (Title IV-D of SSA)	1975	Enforcement of child support orders to the absent parent
Earned Income Tax Credit (EITC)	1975	Refundable federal income tax credit for low to moderate income working individuals and families to compensate for child care costs
Permanency Planning (Title IV-E of SSA)	1980	Assistance in finding a family-like setting for persons under age 22 rather than placement in an institution
Child Care and Development Block Grant	1990	Federal subsidies for child care

on family preservation, however, Title IV-E of the Social Security Act allocated $5 billion to help with adoption and foster care compared to only $300 million under Title IV-B for home services and family preservation. Some fear that this disproportionate allocation to out-of-home services may encourage more out-of-home placements than desirable or necessary. The additional fact of several high-profile child fatalities within the welfare system due to overburdening of child welfare workers has recently led to more of a "rescue and place" or "safety first" emphasis than in the 1980s and 1990s, a trend that some authors decry (Lewandowski and Briar-Lawson 2009b). It must, of course, be recognized that not all families are capable of providing adequate care in cases where a parent is incarcerated, violent, or addicted to drugs or alcohol. In those cases, along with foster care there is a new phenomenon of grandparents who are raising their grandchildren, a development also known as kinship care. In Massachusetts roughly 1 in 20 children are in kinship care (Addison 2007; Nichols 2002).

Juvenile justice. Beginning in the mid to late nineteenth century, the risk for older children and adolescents was getting into trouble, leaving home to go to the city, and there falling into poverty or crime. Child labor laws prevented their employment, and many left school or rural areas where there were no schools beyond the eighth grade. The juvenile courts established between the 1890s and 1920s sought to deal with footloose juveniles. Up until the 1920s the usual treatment was to send the adolescent delinquent to a reform school. Methods for treating juvenile delinquents began to change with the general trend toward deinstitutionalization that took hold in the following decades.

The modern phenomenon of runaway adolescents rose to national attention in the 1960s and raised the question of how such children should be treated (Blehar 1979). Research revealed several possible causes: violence and dysfunction in the family and psychological problems and school-related difficulties of the child. The juvenile courts had been concerned with delinquency ever since the early 1900s, and reform schools and other forms of detention had grown up to handle the problem. In the 1970s, however, an important shift occurred with the passage of the Juvenile Delinquency and Prevention Act of 1974. Responsibility for delinquents was removed from the Department of Child Welfare and placed under the jurisdiction of the Department of Justice. The change was accompanied by important reforms such as a narrower range of juvenile offenses, expansion of due process for juveniles, and more emphasis on treating the offenses and avoiding labeling of the offender. In 2002 the Juvenile Justice Prevention Act further sought to reduce use of institutions and increase support from community and

home-based services. Here too, by reframing a youth's problem as a family issue requiring family-based interventions, it is possible to shift the focus of treatment to other contributing factors. The effect is to make family the focus where various systems cross—mental health, substance abuse, educational problems, disabilities, economic need, and child welfare. The challenge is to shift the focus from punishing the offender to finding solutions for managing a variety of difficulties in an integrated fashion. Although this shift is usually associated with efforts at family preservation, an important exception is in cases of domestic violence and spousal abuse, where the best solution may be protection of the family from an abuser in a homeless shelter (Lewandowski and Briar-Lawson 2009b).

Family-Related Health and Disability Services

As one reviews the great range of American social programs that assist families in their caregiving functions, one powerful theme runs throughout. Except for Medicare and Medicaid that are directed to the whole population over age 65, virtually every entitlement is limited to circumscribed categories of people with a particular need—poor people, children at risk, or individuals with a given disability or risk factor. This principle is especially true in the field of health care, where the 2010 national debate over health reform was pulled between efforts to expand coverage and efforts to control rising costs (Swartz 2009).

Health care is especially relevant to family policy because poor health is not only a result but also one of the causes of poverty and the inability of children to become productive workers as adults. In order for families to perform their reproductive function of giving birth to and nurturing children, parents, workers, and elders, they need outside help to gain access to preventive health care, medical treatment, home-delivered health care services when needed, and environmental protection that reduces pollution and promotes healthy nutrition and exercise.

Over the past century there have been two milestone developments that significantly expanded health-related insurance coverage of children and elders. The first was the 1935 Social Security Act that within Title IV set up health-related services for poor families who were receiving Aid to Dependent Children (ADC, later AFDC). The second was the amendment of the Social Security Act in 1965 to establish Medicare and Medicaid with virtually universal coverage for seniors. Surrounding and embellishing this stream of legislation were special laws and amendments directed to nutrition for mothers and infants, and assessment and care of persons with mental illness and

physical and developmental disabilities. This review focuses only on those aspects of health care policy that are particularly relevant to the family's nurturance and caregiving function. The emphasis is on what kinds of caregiving are available and who qualifies for assistance. The three main types of service are related to family health, mental health, and disabilities and risk factors.

Family Health Care

The origins of a broad-based approach to maternal and child health can be traced to the early 1900s and the work of the Children's Bureau along with several streams of the women's rights movement. Together, their enlightened efforts culminated in the passage of the Sheppard- Towner Act in 1921 that set up clinics for expectant and postpartum mothers and newborns. These services along with programs on health education were available to all women, not just the poor, and were especially welcome in rural areas and small towns where professional medical care was scarce or absent. In just a few years the high rate of infant mortality in needy populations was reduced, and many mothers expressed their deep gratitude for the health and education they had received from the program as well as from the popular publications *Infant Care* and *Prenatal Care* that were put out by the Children's Bureau (Ladd-Taylor 1993). Despite this success critics complained that this "socialist" approach encroached on the rights of doctors so that the law was not extended beyond its expiration in 1928. Not until the Social Security Act of 1935 were elements of this kind of public health approach revived in provisions for health services to children under ADC. But the new provisions were less universal than the Sheppard-Towner provisions and more categorical (in which eligibility is limited by particular characteristics such as age or income). Since 1935, family health coverage has grown through a variety of programs related to nutrition, public health measures (such as inoculations), family planning, expansion of health insurance for children, and most recently, federal legislation to cover the large population of those who are currently uninsured.

Nutrition and food security. In the area of nutrition, one of the first great successes in family policy according to Gilbert Steiner (Steiner and Milius 1976) was the establishment of the National School Lunch Program in 1946. Even though lunches were already delivered in some schools, the important social innovation was involvement of the federal government (with help from the Department of Agriculture) in supplying food that up to then had been considered a basic family responsibility. (I remember in my own rural township school, when I was in seventh grade, the hot lunches

that were wheeled into the classroom on a homemade wooden cart and cost only $.10 each, including $.01 for milk). In the 1960s during the War on Poverty, the Food Stamp program made it possible for low-income families to buy food at reduced cost. This program grew dramatically during the 2008 to 2009 recession to supplement the resources of low-wage workers and their families as well as the unemployed (Deparle and Gebeloff 2010). Another recent sign of public interest in nutrition has been First Lady Michelle Obama's campaign to reduce childhood obesity by improving the choices of what children eat at school and at home, a matter that was once considered to be entirely a private family matter. It is well known that obesity has many long-term negative effects on health and health care expenditures and that in the long run good nutrition serves the public interest as well as the individual.

Maternal and child health. Programs for mothers and children that were authorized under Title IV-A of the 1935 Social Security Act were a direct descendent of the defunct Sheppard-Towner Act of the 1920s but were generally limited to families qualifying for ADC. With the rise in teenage pregnancy during the 1960s and 1970s, new legislation authorized special outreach efforts to promote contraception and family planning. In addition, early screening identified infants with special needs who were eligible for early intervention and follow-up. The Women, Infants, and Children (WIC) program was established in 1972 and continues today to provide supplementary nutrition and health screening to low-income mothers and their children (Klerman 1996; Oliveira et al. 2002).

Expansion of health care coverage. Up until the Social Security Act of 1935, except for the brief life of the Sheppard-Towner Act during the 1920s, there were no general public programs to support medical care. With the passage of the Social Security Act, a two-tier system developed in which public hospitals and clinics provided medical care to the poor and uninsured at no cost. In the two decades following World War II, private insurance coverage expanded, and many employers and labor unions developed benefit plans to cover their workers. With the institution of Medicare and Medicaid in 1965, virtually all persons age 65 or over became eligible for public-supported health insurance, a situation that continues to the present. Medicaid expanded to cover many special groups in the population under 65, but these advances were accompanied by troubling developments. First, the national cost of medical care rose from approximately 8 percent of the total national gross domestic product (GDP) in the 1970s to nearly 17 percent in 2010. Second, despite rising expenditures, the numbers of uninsured steadily

rose to almost one fifth of the total population or approximately 45 million people in 2009 (Swartz 2009).

These problems have led to several recommendations from health economists, principally that the United States move to a system of national health insurance ("single payer" or "public option") that would pool risk across the whole population, thus lowering costs. This is the idea behind the initiative that the Obama Administration undertook during its first two years and which finally succeeded with passage of the Patient Protection and Affordable Care Act of 2010. The national debate over the desirability of universal coverage revealed considerable skepticism on the part of the general public about the need for such reform. Yet in early 2010 before passage of health reform, Congress reauthorized the Children's Health Insurance Program (CHIP) that expanded coverage from 7 million to 11 million children. The program was originally created in 1997 as Title XXI of the Social Security Act and covers children and pregnant women in families with incomes too high to qualify for most state Medicaid programs but too low to afford private coverage (U.S. Department of Health and Human Services 2011b). Another important precedent and step toward national health reform was the adoption by Massachusetts of universal health coverage in 2006. By 2008, coverage had been extended to 439,000 more people, and visits by the uninsured to emergency rooms had dropped by more than a third. The changes to the law resulted in $68 million in savings in the pool of money set aside by the state to cover the uninsured (Lazar 2008).

Mental Health Services

Difficult as it has been to expand coverage for general health expenses, it has been even more difficult to provide basic services and support for mental illness. Yet it is estimated that roughly 28 percent of the adult population in the United States has a mental disorder or chemical dependency, but only 15 percent of the adult population is receiving treatment. The comparable figure for prevalence and services received by children and youth is 20 percent (Surgeon General of the United States 1999:408–409). The impact on families of a troubled youth or an alcoholic or substance-abusing parent is enormous, with negative effects rippling out to school performance, employment, and the stability of the family itself. There is increasing recognition of the importance of treating illness and substance abuse not by placement in an institution but by rehabilitation of the client within the family and community.

The contemporary emphasis on treating an ill person in familiar surroundings rather than in institutions is a drastic departure from the out-of-home placement paradigm that was typical into the 1960s. Persons with diagnoses

of schizophrenia, depression, and senile dementia were routinely placed in locked wards in mental hospitals far from their home communities. During the summer of 1957, I had the remarkable opportunity of serving as a graduate student intern in the social services department of the Apple Creek State School in Apple Creek, Ohio. There I witnessed the bureaucratic and custodial style of a large institution that housed severely retarded individuals along with the mentally ill. Attendants were well meaning, but there was little interaction of the kind that would lead to rehabilitation and release. Everyone recognized even then that conditions were a lot better than they had been. Miracle drugs like chlorpromazine had made the difference. I was shown the padded cells to which very disturbed patients had once been confined. And even at that time further changes were in progress. Elderly patients with dementia were being discharged from the hospital to nursing homes newly set up in large though rundown Victorian houses that were in scattered rural communities throughout northeastern Ohio. I later realized that I was seeing the beginnings of deinstitutionalization, a nation-wide trend that reached its crescendo in the 1960s and 1970s.

Today many state institutions for the mentally ill have been closed. Federal legislation in the 1960s that set up Community Mental Health Centers and established Medicaid (Title XIX) laid the foundation for treatment of psychiatric cases in the community. The discharge of former patients into the community, however, took place before most had gained needed skills for living outside an institution. Nor were needed services made available to help former inmates cope with the new challenge of living independently. The appearance of "bag ladies" and a rise in the number of homeless persons was a direct result. Still, there was a new awareness that mental illness was remediable. The Social Services Block Grant of 1974 (Title XX of the Social Security Act) further provided for an array of social services to needy populations in the community.

Deinstitutionalization shifted the treatment paradigm to the "least restrictive setting," which meant where possible, keeping a patient in the family and the community. Title XX set out five goals with important implications for families. Services should help clients achieve economic self-support; reduce dependency; remedy abuse, neglect, and exploitation of children or adults; prevent or reduce inappropriate institutional care by providing community and home-based care; and use referral to an institution only as a last resort (Kamerman and Kahn 1976:445). Since that time, important demonstration projects in North Carolina and California in the 1980s have shown how individualized treatment plans and case management can provide "wraparound" services in the community for children who are at risk of out-of-home placement. These pioneer efforts demonstrated ways of bringing

together mental health, child welfare, juvenile justice, and special education services to help troubled children and youth. This approach was solidified in 1992 in the Comprehensive Community Mental Health Program for Children and Their Families that provided support to communities "to develop a broad array of community-based, family-based services for children with serious emotional, behavioral or mental disorders" (Knitzer 1996:214). For a summary of these services, see Table 4.3.

Table 4.3   Family-Related Programs for Nutrition and Health Care

Enabling Legislation	Year	Provisions for Nutrition
National School Lunch Program	1946	Subsidized lunches and milk for children in school
Food Stamp Program — Pilot Extended nationwide	1961, 1974	Benefits for low-income households to buy food and avoid hunger and malnutrition
Women, Infants, and Children (WIC) Nutrition Program	1972	Nutrition, health education, and healthy food for pregnant and nursing mothers and children under 5 years old
Enabling Legislation	**Year**	**Provisions for Health Care**
Maternal and Child Health (Title V of SSA)	1935	Access to pre- and post-natal care, treatment and rehabilitation for low-income families and at-risk children
Community Health Services and Facilities Act	1961	Expansion and improvement of community facilities and services for the health care of aged and other persons
Family Planning Services and Population Research Act	1970	Access to comprehensive voluntary family planning services
Comprehensive Community Mental Health Services for Children and Their Families	1992	Creation of community and family-based services for children with serious emotional and behavioral disorders
Children's Health Insurance Program (CHIP), (Title XXI of SSA Reauthorized)	1997 2009	State/federal partnerships cover uninsured children, pregnant women in families with incomes above most state Medicaid limits and too low to afford private health insurance
Patient Protection and Affordable Care Act "Health Care Reform"	2010	Expanded insurance coverage to uninsured; expansion of Medicaid eligibility, premium incentives for employers, acceptance of pre-existing conditions

More recently, the establishment of the New Freedom Commission by President George W. Bush in 2002 has led to an agenda for wholesale transformation of the mental health system and *The Federal Action Agenda* of 2005. Key goals are to send a message that children and adults can *recover* from serious emotional disorders and that treatment should be consumer and family driven. In 2006, the Federal National Partnership for Transforming Child and Mental Health and Substance Abuse Prevention and Treatment began the work of translating these goals into practice by working on the issue of suicide prevention along with other top priorities such as integration of primary health and mental health services. Among the first-year accomplishments was a consensus statement that "Adults with serious mental illnesses and substance abuse disorders and children with serious emotional disturbances can and do recover" (U.S. Department of Health and Human Services 2008).

As a follow-up to this agenda, the Substance Abuse and Mental Health Services Administration (SAMHSA) awarded nine grants to nine states as incentives to reduce fragmentation of services across systems. The entire agenda, together with a treatment philosophy that seeks to "empower individuals to be responsible for their own self care," is evidence of the profound revolution that has occurred in the field of mental health in the last 50 years (U.S. Department of Health and Human Services 2008:5). No longer are persons with mental illness or serious addictions locked away out of sight of friends and family, there to languish sometimes for the rest of their lives. The whole treatment philosophy has shifted to treat mental illness as part of a larger spectrum of impairments that can be overcome. Central to the process is respect for the individual, integration of community-based services, and heavy reliance on help from peers and families.

Provision for Disabilities and Coping with Risk Factors

The transformation of the mental health treatment paradigm presented in President Bush's 2001 New Freedom Initiative builds on the 1990 Americans with Disabilities Act (ADA) and the Supreme Court's 2002 decision in *Olmstead v. L. C.* that emphasizes the requirement that services be provided in the community to the maximum extent possible rather than in an institution (Shirk 2008). Especially with respect to those with intellectual disabilities, it took many decades to accomplish this about face. Only through the sustained efforts of enlightened professionals and determined parents did the general public begin to understand that citizens with mental limitation could live independently outside of institutions (Dybwad 1990). Beginning in 1972 with Chapter 766, in Massachusetts the law required that children with

learning disabilities and "special needs" be accommodated in public schools. At the federal level in 1973 Congress passed Section 504 of the Rehabilitation Act that required free public education for children with disabilities. The Education for All Handicapped Children Act (EAHCA) also guaranteed all children with any handicap a public education. This legislation has been reauthorized several times since the 1980s as the Individuals with Disabilities Education Act (IDEA) and provides the foundation for inclusive schooling which requires that every child with a disability be offered a free and appropriate public education in the least restrictive environment (Villa and Thousand 2005). The larger disability rights movement has helped bring families and communities back into the center of the service picture by establishing two principles: first, access to free and appropriate public education; and second, provision of help in the least restrictive environment.

Education and early intervention. In 1975, the Education for All Handicapped Children Act (EAHCA) mandated early intervention for children at risk because of poverty or signs of developmental risk such as delayed speech, motor impairment, very low birth weight, or conditions like Down syndrome or cerebral palsy (S. Allen 2009).

Belief that early intervention would lead to much better outcomes for persons with a disability was founded on the research and activism of psychologists like Urie Bronfenbrenner and Edward Zigler and on the precedent established by the Perry Preschool Project in Michigan in the 1950s and the federal Head Start program begun in the 1960s. During the War on Poverty, the idea had developed that helping poor children to get an early start on their education would make them more likely to succeed later on. Early investment would thus pay off in dollars saved on prisons, social services, and costs of unemployment. While such cause-and-effect relationships were never proved for Head Start, they had been shown for the experimental Perry Preschool Project, which provided an enriched program of early childhood education to poor children. Follow-up studies of the Perry students estimated that for every $1 spent on the program $3 were saved in public funds due to reduced criminality, better educational attainment, and greater self-sufficiency. These findings contributed to the public enthusiasm for Head Start and gave a general aura of legitimacy and support to the whole idea of early intervention (Zigler, Marsland, and Lord 2009).

From a family perspective, the development of what is called an Individualized Educational Plan or IEP was an important turning point because the old system of care for children with disabilities had been dominated by medical experts. It was replaced by a new system that gave a greater role to family decision making and community-based services. The creation of each

IEP requires a meeting of a parent with the child's teacher to work out the most productive learning plan for the child (Dembowitz 2007). At the preschool level, it is social workers or their representatives who work with families to assess the nature of the child's risk factors or delays and to identify compensatory developmental tasks for work with the infant or toddler (S. Allen 2009; J. Gallagher 1996). Home-based services include work with parents on nursing and nutrition, behavior management, and various other parenting skills. Medicaid pays for these services. However, while poor children make up 70 percent of the target population to be served by Medicaid, the funds are disproportionately allocated to that 15 percent of the eligible recipients who live in institutions for the mentally ill or mentally retarded and to another 15 percent of disabled elderly living in nursing homes (National Council on Disability 2005). Over half of Medicaid funds are going to persons confined to institutional settings. By favoring institutional over home-based placements, this funding pattern weakens the effort to provide treatment in the least restrictive setting.

The disability rights movement. In contrast with many of the social welfare programs directed to persons with mental or physical limitations which rely on a medical model of treatment, the disability rights movement took its cue from civil rights. From the 1970s on, leaders of the movement worked to change people's thinking from wanting to "cure" a handicap or make disabled people well again to thinking of persons with disabilities as being healthy but as suffering from discrimination based on "ableism" in which the world is not set up to allow them to function independently and effectively.

Throughout the period that handicapped children's rights to education were being expanded, demographics of disability were changing. More children were alive who would once have died in infancy. Many more older people were surviving into later years when disabilities become more common. In addition, brain injuries, motorcycle accidents, and other traumas were increasing the numbers of young adults with disabilities. The civil rights movement was spreading to disabled adults and their families. The groundwork had been laid in Sections 501–504 of the Rehabilitation Act of 1973. It was followed by the Education for All Handicapped Children Act (later known as IDEA). These laws, along with several important court decisions, culminated in passage of the Americans with Disabilities Act (ADA) in 1990. ADA required accommodations in architecture and construction of new public buildings. Principles of "universal design" were implemented to create curb cuts, accessible public toilets, ramps and elevators, and both lighted and audible signals that could be used not only by those in wheelchairs or those who were blind or deaf, but also by people wheeling strollers, or

elders with physical limitations (Hehir 2002). The ADA further protected persons with disabilities against discrimination in employment and provision of state and local services. The ADA protects not only those with *current* physical or mental impairments "that substantially limit a major life activity such as walking, seeing, hearing, learning, breathing, caring for oneself or working" (Fleischer and Zames 2001:93). It also covers those who have a *history* of impairment such as cancer, mental illness, addiction, or HIV. The U.S. Census Bureau (2009a) estimates that there are over 42 million Americans with disabilities who are living outside of institutions—almost 15 percent of the civilian population. For a summary of legislation that has authorized programs for persons with disabilities, see Table 4.4.

Imbedded in the new accommodations is a new kind of thinking by persons with disabilities. Rather than seeing themselves as sick or damaged and therefore in need of medical treatment, some individuals with handicapping

Table 4.4   Provisions for Persons with Disabilities

Enabling Legislation	Year	Provisions
Aid to Blind (Title X of SSA) Aid to Disabled (Title XIV of SSA)	1935–1970 1956–1974	Grants to the states for Aid to the Blind Grants to the states for the permanently and totally disabled
Rehabilitation Act (Section 504)	1973	Right to a free public education for children with disabilities
Education for All Handicapped Children Act (EAHCA)	1973	Right to inclusive schooling
Individuals with Disabilities Education Act (IDEA)	1975	Early intervention with Individualized Educational Plan (IEP)
Social Services Block Grant (Title XX of SSA)	1974	Funding for states to provide social services to promote self-sufficiency, to prevent abuse or neglect, and to prevent or reduce inappropriate institutionalization
Americans with Disabilities Act (ADA)	1990	Requirement of public accommodations for persons with disabilities
Olmstead v. L. C.	2002	Ruling by U.S. Supreme Court that services be provided *in the least restrictive setting*

conditions have claimed their rights as citizens to freedom of choice, and self-determination as to where they can go, how they should live, what to eat, and where to sleep. In their activism they have combined disability rights with civil rights to demand the just treatment of all citizens. This attitude questioned the prevailing medical model of treating the disabled person as a patient in order to make him better (which was futile) or to get him to accept his limitations and lack of choice as inevitable. The first line of battle was to resist confinement to a nursing home, which has historically been the typical disposition of persons with severe impairments such as cerebral palsy or paralysis of the limbs (Shapiro 1993:252). The next big battles were to set up alternative living arrangements in handicap-accessible apartments with technological aids and personal assistants to enable the residents to take employment, freely associate with others, and make basic choices of daily living on their own terms (O'Brien 2004).

The principle that persons with disabilities should have equal rights to public accommodations, employment, and public services was eventually joined with the idea that they also have equal rights to the kind of social services that most people prefer—delivered to them in their homes or local communities where they can exercise greater autonomy than in a regimented institutional setting. This principle was tested in the landmark Supreme Court case of *Olmstead v. L. C.* (2002), which resulted in a majority decision that persons with disabilities have a right to treatment *in the least restrictive setting* that is appropriate to their situation. The court required the state of Georgia to provide services that up to that time had been denied to L. C. even though professionals had recommended her release to the community. The *Olmstead* decision thereby legitimated home- and community-based treatment and services and required the states to provide them. With *Olmstead,* institutional placement was finally relegated to second choice in treatment of those with serious handicapping conditions.

Now, with the requirement to offer services in the least restrictive environment, the prevailing system for providing long-term services is clearly inadequate on several grounds. There is a mismatch between available alternatives and the mandate to provide care primarily outside of institutions. In addition, the actual disbursement of Medicaid funds goes primarily to long-term care institutions. It is also worrisome that as much as 22 percent of total state budgets go to payment of Medicaid costs, a figure that will become increasingly unsustainable as more people experience disability and as older people live longer with more disabilities. The solution proposed by the National Council on Disability (2005) is to universalize the provision of social services to persons with disabilities. This goal would be accomplished

in two principal ways: first, by making middle-income people eligible (who presumably can help pay for some part of the services), and not just the poor; and second, by including people in the middle years, and not just children and people age 65 or older. Delivery of services also should become much more family oriented and community based. Such a change would recognize and support family members and neighbors who in their role as informal caregivers currently provide more than $200 billion worth of unpaid services in their local communities.

Not only the civil rights argument for greater choice and social justice for disabled citizens, but also the need to contain health care costs, is helping to drive the shift from institutionalized care to private accommodations in the local community. The cost savings are stunning. Way back in the 1980s, an experiment by Julian Sanchez, a paraplegic in college in Utah, showed that provision of a personal assistant three hours a day cost only *one-fifth* what it had cost to keep him in a nursing home (Shapiro 1993). A recent Massachusetts experiment using Medicaid to divert elders with disabilities from nursing homes and pay for their foster care in private homes has saved the Commonwealth almost $16 million (Seniorlink, Inc. 2009).

The Caregiver Workforce

Across the major types of caregiving from aging and childcare to accommodations for disability, several stages of change can be observed. The starting point, representing most of human history, was informal care given almost entirely by individual family members, neighbors, friends, and relatives. A big change occurred when industrialization and modernization split off paid work from family life. During that time, care for the most severe cases of mental and physical illness was placed in institutions and not kept at home. In the past half century, the trend toward deinstitutionalization and "mainstreaming" has introduced a third major stage of development: Many who would earlier have been consigned to institutions are once again in the care of families and the community. Nevertheless, many functions such as cooking, sewing, and other types of home production that left the home with industrialization will probably never return.

Given the vast amount of service and caregiving outside the family, it is easy to understand why there has been a massive growth in the numbers of caring professionals such as physicians, nurses, teachers, and social workers. In addition, many paid employees work in food preparation, cleaning establishments such as laundries and dry cleaners, and maintenance jobs that

were once done within the household. This growth of the helping professions and service work has enabled families to get help with care of children, elders, and those with special needs. Nonetheless, the great bulk of assistance for persons who need help—whether they are seniors, children, or persons with some type of physical or mental impairment—still comes from family members.

With the rise in married women's and mothers' labor force participation, it is clear that this vast assemblage of both unpaid and paid care workers is needed. Yet there are some recurring patterns of gender, race, and social class inequality among both family caregivers and service workers that call for critical attention. In addition, there is a long-running concern that quality of care in long-term care institutions such as nursing homes is badly in need of improvement and will only be accomplished by addressing the organization, training, and incentives of the workforce (R. I. Stone 2006). The following account outlines four themes: (1) the continuing importance of informal caregiving; (2) the heavy representation of women and minorities among professional caregivers and service workers; (3) the conflict between the mandates of efficiency and care; and (4) the current trend toward care in the community.

Informal Caregiving

In the realm of childcare, there are all the mothers and fathers who care for their children as a regular part of family life. Bianchi and Raley (2005) found that mothers' hours of caring for children were somewhat higher in 2000 (13 hours) than in 1965 (10 hours). Fathers' hours more than doubled, from three hours per week in 1965 to seven hours per week in 2000. These changes were made possible by an increase in multitasking (e.g., watching the children while doing grocery shopping) and by a decrease of almost 15 hours per week in the amount of time spent in housework.

The National Council on Disability (2005) reports that 44.4 million American caregivers provide unpaid care to adults who have some impairment or disability, and 60 percent of these caregivers also have other jobs that are paid. Bookman and Harrington (2007:1005) make clear the important role of family members and other informal caregivers in safeguarding the well-being of an older person in an appointment with the doctor and in everyday life in a nursing home. Their fieldwork with family caregivers revealed that "family caregivers—untrained, unsupported, and unseen—constitute a 'shadow-workforce,' acting as geriatric care managers, medical record keepers, paramedics and patient advocates to fill dangerous gaps in a system that is uncoordinated, fragmented, bureaucratic, and often

depersonalized." They conclude that the health care system lacks coordinated care and information and therefore spouses, adult children, or other relatives perform important integrative functions and in so doing raise not only the quality of care, but also help to reduce the costs.

Women and Minorities as Paid Caregivers

The caregiver workforce has a persistent profile. Women and minorities predominate, and they typically receive lower pay and fewer benefits than employees in other occupations who have comparable education and responsibilities. Throughout the world, even in the Scandinavian countries with their very generous subsidies for childcare and elder care, there is very strong sex segregation in the service professions and occupations. Not only do women predominate, their pay scale is low relative to other service jobs performed by men. In the heyday of calls for "comparable worth," an often-quoted statistic was that tree trimmers in Denver, Colorado, earned more than nurses; and that child care workers received pay that was comparable to that of a parking lot attendant. In an analysis of over a thousand occupations from the 1980 census, England (1992) found that in occupations with a high proportion of women, men earn less than men in other occupations with comparable skill and effort. But the biggest single factor in lowering pay of a given occupation was whether it required nurturance (i.e., caring behavior). Findings from the National Longitudinal Survey of Youth for 1982 through 1993 support a similar conclusion and show that "working in a caring occupation leads to a significant net wage penalty of 5–6 percent for both men and women" (England, Budig, and Folbre 2002:464). Chafetz (1991) explains the wage penalty for female occupations as the result of the socialization process that allocates greater power and resources to males. Males learn to break away from identification with their mothers and thus adopt impersonal and business-like styles of behavior whereas females are encouraged to imitate their mothers in concern for others' well-being. Public life implicitly favors the male work style as more professional and rational. The emotional aspect of caring for others is relatively devalued as something that is natural, that anyone can do, and that is therefore worth less pay than work in a male-typed occupation.

Duffy (2005) has tested some of these theories to see whether they are borne out by U.S. Census data over the past century. She examined whether paid care was connected to inequality of gender, race, ethnicity, and immigration status and whether the relationship had changed over time. She found that care workers are indeed part of a stratified labor market with a primary sector of professional jobs that are relatively secure,

and a secondary sector that is more part-time and insecure and subject to temporary employment and layoffs. The primary sector comprises nurturant professions such as physicians, clergy, teachers, nurses, and therapists, whereas the secondary sector is made up of non-nurturant service jobs in food preparation, janitorial work, health care, and private households. The primary sector is dominated by white women, whereas the secondary sector is dominated by people of color, ethnic minorities, and recent immigrants. A remarkable collection of the personal stories of women domestics and their aspirations for their daughters can be found in the work of Evelyn Nakano Glenn (1992), a professor of sociology at the University of California at Berkeley, whose own mother was sent to a Japanese internment camp during World War II and who worked as a domestic so that her children could gain an education and have a better life. Parallel stories from black domestics in the South and Mexican American women in the Southwest show that a similar pattern still persists today among the newest immigrants. However, there is the question of whether they will have the same opportunity for upward mobility as earlier generations. Today there is a new global market that brings mothers from the Third World to America. They have left their own children behind in the care of other family members so that they can send cash back home. But the long absences from their own children, coupled with low pay and often-oppressive working conditions, make upward mobility a distant if not impossible goal (A. R. Hochschild 2001).

Glenn contends that several radical changes are necessary to raise the status of caregivers. Similar to the spirit of the Disability Act, every citizen should have the right to receive care when it is needed, and society should treat caregiving as an obligation not only of families but of the nation as a whole. Employers should make it more possible for people to integrate caregiving with work. To make these changes, a fundamental reorientation is necessary in which "the liberal concept of 'society' as made up of discrete, independent, and freely choosing individuals will have to be discarded in favor of notions of interdependence among not wholly autonomous members of a society" (E. Glenn 2001:93).

Bureaucratic Efficiency versus Personalized Care

During the past two decades, a number of feminist scholars have subjected caregiving to a critical perspective. They have been primarily concerned with how paying for caregiving affects the quality of care. Nancy Foner (1994), an anthropologist, conducted fieldwork during 1988 and 1989 in a New York nursing home and documented the inherent conflict

between the profit motive and the caregiving ethic in a business enterprise that provides long-term care. The demand for efficiency conflicts with the need to give care and personal attention and show concern for the well-being of each person. Foner compares the situation to Max Weber's "iron cage of bureaucracy" and uses Weber's theory as her basic analytic framework for understanding the behavior that she observed (Weber 1968). Some nurses took time with patients to give them a hug and a smile, but they were criticized for not getting the work done fast enough. Others who were stern and demanding were allowed to be almost abusive in language and demeanor because they finished their work on time. Efficiency trumped caring. Similar observations are made by D. Stone (2000:110) who summarizes the basic principle of bureaucratized care: "Love is taboo; detachment is correct."

Community Care Built on Relationships

Against a general backdrop of the creeping takeover of informal and personalized care by bureaucratic and profit-oriented institutions and care workers, a key question is how to preserve humane and high-quality care in the face of heartless routine. Fortunately, a revolution is afoot in the demands of those who seek care as well as in the managerial science of caregiving. The movement for innovation that would give more control to the client started in the disability rights movement. During the 1990s, protests by disabled people put a spotlight on the right to independent living and to hire their own care providers rather than be subjected to rigid bureaucratic requirements. This action led to a big shift from payments based on eligibility criteria to payments based on type of care needed and to the individual's control over contractual arrangements. Caregiver allowances were paid through Social Security and the tax system to the care user who could then pay the wages of caregivers (Ungerson 2000). Changes during the 1980s and 1990s in the way services were being delivered to children with disabilities also had the effect of wresting power to provide care from the agencies and making it more individualized and family centered. Services for children under IDEA became more interdisciplinary and integrated across therapies. Transitions were better coordinated between infant–toddler and preschool programs (Harbin, McWilliam, and Gallagher 2000). In short, the evolution of family–professional partnerships had been transformed from a focus on counseling and psychotherapy in the 1950s and 1960s to parent training and involvement in the family-centered model from the 1960s to the 1980s, and finally a focus on collaborative empowerment in the 1990s (Turnbull, Turbiville, and Turnbull 2000).

Along with these changes on the ground has come a transformation in the managerial science that guides the health care and services industries. Gittell (2009) uses a relational model to understand the phenomenal success of Southwest Airlines by identifying those features of organizational behavior that are needed for the best and most efficient delivery of caregiving. Gittell shows that Southwest Airlines was able to lead the industry in on-time departures, customer satisfaction, and profitability because flight attendants, mechanics, pilots, and reservation agents were able to work across job boundaries. They had similar goals, shared knowledge, and mutual respect. In research on the orthopedic surgery units of nine hospitals in Boston and New York, Gittell shows that the hospital with the best relational coordination also had the shortest hospital stays, highest potential patient satisfaction, and best surgical outcomes as measured by lower postoperative pain, lower readmission rates, and lower mortality. She identifies the creation of "care paths" that enable specialists to integrate the goals and knowledge across job boundaries as the key ingredient to such success. These care paths, or care protocols, outline a necessary and standard set of procedures that are critical to patient well-being. Having a shared protocol assures that all the specialists will work together to see that each critical step is followed. Signs that such a system might be emerging in family caregiving come from a GAO report that describes state agencies that use a similar integrative strategy to coordinate health care and meet the needs of children in the foster care system (U.S. Government Accountability Office 2009). Application of relational methods is a very promising development that hopefully will be replicated in many other types of caregiving, from long-term care for the elderly to services for younger persons with a variety of special needs.

Nevertheless, there are inevitable dilemmas in how to reach the right balance between informal family-based caregiving and caregiving that must be done inside formal institutions. How can sensitivity to the patient's particular desires and characteristics be encouraged and maintained? Is it possible to compensate family members for giving care, even though such a practice raises issues of accountability, documentation, and quality assurance? Most people know someone confined to a nursing home or assisted-living facility who does not want to be there but for whom living at home is not an available option. How to manage these cases is still an unsolved problem. One of the most promising initiatives is the Green House Project, which strives to create small, homelike living units within a larger institution. The setting, even though it is part of a larger institution, encourages the intimacy and sensitivity to individual personalities and preferences that comes the closest to living in a family and a homelike setting (Green House Project, 2011).

The Robert Wood Johnson Foundation (2010) sees in it a major culture change in the way long-term elder care is delivered and describes it as,

> A model that breaks the mold of institutional care by creating small homes for six to 10 "elders" who require skilled nursing or assisted living care. The homes, which are designed for the purpose of offering "privacy, autonomy, support, enjoyment, and a place to call home," are a radical departure from traditional skilled nursing facilities and are considered to be the peak of culture change.

Conclusion

Most Americans view their national family policy as almost nonexistent in comparison with the robust programs of European countries. But the actual array of U.S. programs for helping seniors, children, and persons with mental or physical impairments is really quite extensive. Historically, the helping services were small, often privately supported, and limited to the neediest cases. Today, however, caregiving services are both more extensive and more specialized to meet the needs of different populations, and they account for a large portion of state and federal budgets. Even as public policies to support caregiving have expanded, there has been a turn away from bureaucratic and profit-oriented institutions as the preferred place of treatment. Experts and users recommend returning more of caregiving to the oversight of individuals, families, and the local community. These themes are visible in all three types of care that are covered in this chapter: care for older people, children, and persons with disabilities.

Programs for care of the aged grew up as a response to a long-term increase in the elderly population as well as modernization of the family and the economy that pushed many seniors into dependency and women, the traditional caretakers, into the paid labor force. Civil War and railroad pensions of the nineteenth century provided a template for the Social Security program established in 1935 that now provides income support and health care to almost everyone over age 65. Current challenges are to sustain these programs even as costs continue to grow. The main strategies are to encourage private savings, healthy aging, and prevention of disability, as well as cooperation of informal family caregivers with experts in the community.

Expansion of programs for children also took place alongside a demographic revolution that lowered infant mortality, led to smaller families, and resulted in greater relative attention to the well-being of each child. Decline of the rural economy and loss of the family's productive function to outside firms also made it clear that child labor was no longer a viable source of family income. What was needed instead were learning and education that

would prepare future workers for productive roles in modern society. In the absence of a breadwinner, the family needed income which in the early twentieth century was provided by mothers' pensions, then after 1935 was supported by ADC, then AFDC, with aid to dependent children, and finally after welfare reform in 1996 by TANF (Transitional Assistance to Needy Families). Childcare that began with the settlement houses of the nineteenth century grew into the public programs for Head Start and private cooperatives that emerged in the 1960s and 1970s. Although public funds for care of preschool children are still targeted primarily to low-income families, childcare outside the family for preschool children has become a widespread phenomenon. Yet many experts agree that for long-term productivity of the nation, the years between birth and age 3 are especially critical for optimum development and better life chances.

In addition to helping families with such basic functions as childcare or income support, the child welfare field also has historically been concerned with how to provide assistance when a family is not able to function in the normal way. Programs for protection of children from neglect and abuse, arrangements for foster care, and provisions for treatment of juvenile offenders are all examples of other aspects of caregiving in the field of child welfare. The trend toward deinstitutionalization and working with families and the local community to stabilize and treat these difficult cases has become the new goal among experts in the field.

Health care reform and the disability rights movement have built on the accomplishments and progress that have occurred in elder care and child welfare. Two main themes are the trend toward universal access and the trend toward de-institutionalization. Several nutritional programs illustrate the theme of broader access. The establishment in 1946 of the National School Lunch Program and of the Women, Infants, and Children (WIC) program in 1972 guaranteed nutritional support to children that came from outside the family. The Food Stamp program, established in the 1960s, has helped families faced with low wages and unemployment during the 2008 to 2009 recession. Mental health professionals also advocate broader access to treatment for mental illness, alcoholism, and substance abuse. However, it is especially the disability rights movement that has made the clearest and most insistent claims for equal access and individual control. By using the model of the civil rights movement to identify and resist discrimination against persons with disabilities, advocates built on a series of laws to provide public education to handicapped children and social services to the elderly that culminated in the Americans with Disabilities Act of 1990. Two desired results have occurred. There is agreement that treatment should be given in the *least restrictive setting* (i.e., outside an institution). It should also be

possible, in those situations where the person with a disability is otherwise healthy, to hire one's own caregiver and live independently in one's own home with needed services being delivered there rather than being available only in an institution.

Along with these changes in access and standards of care, the caregiving workforce must also be taken into account. Not only are care workers underpaid relative to others with comparable education and skill, but they also are disproportionately of minority status—women, persons of color, or immigrants—who in general suffer the insecurity of existing on the lower rungs of the occupational ladder.

Fortunately, the new paradigm of working with families and communities to provide care rather than relying primarily on bureaucratic institutions may come to the aid of care workers by releasing them from some of the rigid demands of profitability and efficiency and revitalizing the expectation of humane and personalized care. Similarly, the new managerial science of building on relationships across caregiving specialties can raise the level of mutual respect among clients, professionals, aides, and service workers. If this happens, caregiving that has been given by the family to outsiders will become family-like, with benefits for those who are receiving care as well as those who are giving it.