

Executive Summary

State Residential Services

Number and Size of Residential Settings

The number of state residential settings increased in Fiscal Year 2002. On June 30, 2002 states were directly operating 2,353 residential settings housing persons with intellectual disabilities and related developmental disabilities (ID/DD), 543 less than in the previous year. Of these 2,320 were facilities, special units or other settings primarily serving persons with ID/DD and 33 were facilities primarily serving persons with psychiatric disabilities. Nine-tenths (90.0%) of the state ID/DD settings had 15 or fewer residents, a proportion that decreased slightly from June 2001 (91.6%).

On June 30, 2002 every state except Alaska, District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia was operating at least one large state ID/DD facility. New Hampshire closed its only large (16 or more residents) state ID/DD facility in January 1991. In Fiscal Year 1994 Vermont, Rhode Island and the District of Columbia closed the last of their large state ID/DD facilities. New Mexico followed in Fiscal Year 1995 and Alaska did the same in 1997. In 1999, Maine's last large facility dropped below 16 residents and West Virginia and Hawaii closed the last of their large state ID/DD facilities.

The number of state community residential settings continues to grow and New York remains by far the largest operator of state community residences. State community settings (15 or fewer residents) decreased by 20% (522 settings) to a total of 2,087 in Fiscal Year 2002. By the end of Fiscal Year 2002, New York had 730 state community settings or 35.0% of the national total.

Number of Residents

The population of large state ID/DD facilities continues to fall. The population of large state ID/DD facilities on June 30, 2002 was 44,066, a decrease of 4.1% from June 30, 2001, continuing a trend first evident in Fiscal Year 1968. Between Fiscal Years 1980 and 2002 large state ID/DD facilities' average

daily populations decreased by 86,745 (66.2%) to 44,343 individuals. More than three-fourths (40) of all states reduced the average daily populations of their large state ID/DD facilities by 50% or more during the period.

The population of state community residential settings decreased in Fiscal Year 2002. During Fiscal Year 2002 the number of persons residing in state community settings (15 or fewer residents) decreased 1.0%, to an end of year total of 12,561 persons. The average number of residents per state community setting decreased to 4.4 from the 2001 level of 4.5 residents. New York accounted for nearly three-fifths (59.8%) of all residents of state community settings.

The population of persons with ID/DD in all large state residential facilities continues to decline. On June 30, 2002, the combined population of residents with ID/DD in large state ID/DD and psychiatric facilities was 44,333, a decrease of 4.7% from 2001. The estimated population of persons with ID/DD in state psychiatric facilities dropped from a population of 31,884 in 1970 and 9,405 in 1980 to 267 in 2002.

Nationally, the population of large state ID/DD facilities per 100,000 of the general population continues to fall. On June 30, 2002 there were 15.3 persons in large state ID/DD facilities per 100,000 of the general U.S. population. This compares with 16.1 persons in 2001; 16.8 in 2000; 18.0 in 1999; 19.0 in 1998; 20.0 in 1997; 21.9 in 1996; 23.5 in June 1995; and 99.7 in June 1967. Placement rates in 10 states were at 150% or more of the national average, while in 6 states with large ID/DD facilities they were less than half the national average.

A number of states made very substantial reductions in their large state ID/DD facility average daily populations between 1990 and 2002. The average daily number of persons with ID/DD living in large state ID/DD facilities decreased by 47.5% between Fiscal Year 1990 and Fiscal Year 2002. The largest proportional decreases in large state ID/DD facility average daily populations were, of course, in

Alaska, the District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia which closed all their large state ID/DD facilities. In addition, 20 other states reduced their large state ID/DD facility populations by more than 50% over the twelve-year period.

Admissions, Discharges, and Deaths

Admissions to large state ID/DD facilities decreased very slightly in 2002. In Fiscal Year 2002 an estimated total of 2,149 persons with ID/DD were admitted to large state ID/DD facilities, an increase of 11.5% from the previous year. Admissions were equal to 4.8% of the average daily population of these facilities during the year. Two states reported no admissions to their large state ID/DD facilities. Ten states reported admissions exceeding 10% of their average daily population.

Discharge rates from large state ID/DD facilities decreased substantially in 2002. In 2002 an estimated total of 2,785 persons with ID/DD were discharged from large state ID/DD facilities, an increase of 14.5% from 2,433 in 2001. Discharges were equal to 6.3% of the year's average daily population of those facilities (as compared with 5.3% in 2001). In 2002, 7 states reported discharges that equaled 20% or more of the average daily population of their large ID/DD facilities. Sixteen states with large state ID/DD facilities had discharges less than 5% of their average daily population.

The death rate among residents of large state ID/DD facilities in 2002 (1.9%) was within the range evident throughout the past decade. In 2002 a total of 803 persons with ID/DD died while residing in large state ID/DD facilities. The 1.8% death rate of 2002 is below the 2.0 death rate of 2001, and 1.9% in 1999 and 2000 but above recent rates of 1.7% in 1998, 1.4% in 1997, 1.7% in 1996, 1.7% in 1995, 1.5% in 1994, 1.6% in 1993, 1.4% in 1992 and 1.4% in 1990. The small increases in institutional death rates in recent years may be attributed to the aging and more severely impaired populations of large ID/DD facilities.

Expenditures

In 2002 expenditures for care in large state ID/DD facilities continued to increase and reached a national annual average of \$125,746.15 per person. Between 2001 and 2002 the average annual

expenditures for care in large state ID/DD facilities increased 6.6% from \$121,406.09 to \$125,746.15 (or an average of \$344.51 per day). Twenty-three states exceeded an average of \$350 per day; 23 states reported annual expenditures per resident exceeding the national average. The increase between 2001 and 2002 (3.6%) was much less than the 5.8% increase from 2000 to 2001. The average annual increase for the period 1990-2002 (6.3%) remained well below the 15.0% average annual increase between 1970 and 1989.

Facility Closures

The closure of large state ID/DD facilities continues. Three large ID/DD facilities were closed in FY02; 2 in Illinois and 1 in Michigan in Fiscal Year 2002. Between 1996 and 2002, 45 large state ID/DD facilities were closed, an average of 6.5 closures per year. This compares with an average of 1.25 per year between 1976 and 1979, 3.5 per year between 1980 and 1983, 2.75 per year between 1984 and 1987, 8.75 per year between 1988 and 1991, and 12.5 per year between 1992 and 1995. States report that two additional large state ID/DD facilities are projected to be closed in Fiscal Year 2003.

Resident Characteristics

The number of children and youth in large state ID/DD facilities continues to decrease rapidly, substantially more rapidly than the state ID/DD facility populations as a whole. On June 30, 2002 an estimated 1,983 state ID/DD facility residents (4.5% of the total) were 21 years or younger. This compares with 2,130 (4.5%) on June 30, 2000, 6,944 (8.7%) on June 30, 1991, 54,120 (35.8% of the total) on June 30, 1977 and 91,590 (48.9% of the total) on June 30, 1965. Children who were 14 years or younger made up only 0.7% of state ID/DD populations in 2002 as compared with 2.3% in 1991. At least 21 states had no large state facility residents who were less than 15 years old.

Large state ID/DD facility populations are overwhelmingly made up of non-elderly adults and increasingly of middle-aged adults. On June 30, 2002 86.3% of large state ID/DD facility residents were between 22 and 62 years old. This compares with 60.5% in 1977, 73.1% in 1982, 81.4% in 1987 and 84.3% in 1991. More than one-half (55.4%) of state ID/DD facility residents in 2002 were in the 40-62 year age range. This compares with 19.2% in 1977, 22.9%

in 1982, 27.3% in 1987, 32.5% in 1991, and 52.7% in 2000. This reflects the maturing of the “baby boom” cohort into middle age.

The number of large ID/DD facility residents of 63 years and older has declined by nearly 1,100 since 1977, even as the proportion of “aging” residents has increased. On June 30, 1977 there were 5,590 persons 63 years or older in large state ID/DD facilities; on June 30, 2002 there were an estimated 4,051. However, as populations of large state ID/DD facilities have been reduced by more than 70% over the same period, the proportion of persons 63 years and older has increased substantially (3.7% in 1977, 5.0% in 1982, 6.0% in 1987, 7.0% in 1991 and 8.8% in 1998, 8.4% in 2000 and 9.2% in 2002).

The proportion of ID/DD facility populations made up of persons with the most severe cognitive impairments continues to grow. On June 30, 2002, 63.0% of all residents of large state ID/DD facilities were reported to have profound intellectual disabilities. This compares with 45.6% in 1977, 56.2% in 1982, 63.0% in 1987, 64.8% in 1991 and 64.6% in 1998. Persons with mild or moderate intellectual disabilities made up 20.3% of state facility residents on June 30, 2002. This compares with 26.8% of state institution residents in 1977, 19.6% in 1982, 17.0% in 1987, 16.1% in 1991 and 17.1% in 1998. On June 30, 2002 almost half of all state ID/DD facility residents (48.9%) were persons with profound intellectual disabilities between the ages of 22 and 54 years old.

Although the proportion of persons found with intellectual disabilities among large state ID/DD populations continues to grow, their actual numbers continue to decrease. Between June 30, 1977 and June 30, 2002 the estimated number of persons with profound intellectual disabilities living in large state ID/DD facilities decreased by more than 40,000 (from 68,907 to 27,777). This compares to an increase of nearly 20,000 state facility residents with profound intellectual disabilities between 1964 and 1977.

The proportion of large state ID/DD facility residents with significant functional impairments continues to increase. On June 30, 2002, 37.0% of state facility residents were reported to be unable to

walk without assistance. This compares with 23.3% in 1977, 25.5% in 1982, 29.5% in 1987 and 32.4% in 1991. However, the total number of state facility residents unable to walk without assistance decreased by 20,232 between 1977 and 2002 (from 35,200 to 14,968). Similarly, in 2002, 56.1% of state facility residents were reported to be unable to toilet themselves independently. This compares with 34.1% in 1977. But between 1977 and 2002 the total number of people living in large state facilities who were unable to toilet themselves independently actually decreased by over 18,000 persons.

Most large state ID/DD facility residents are 40 years or older. With the increasing proportions of residents in both middle-aged (40-62 years) and aging (63 years or older) categories, on June 30, 2002 the majority (64.6%) of large state ID/DD facility residents were at least 40 years old. This compares with one-third (33.3%) of all residents 14 years earlier.

Almost half (47.0%) of large state facility residents have 2 or more sensory, neurological or behavioral conditions in addition to intellectual disabilities. On June 30, 2002 13.5% of large state ID/DD facility residents were reported to be functionally blind and 6.6% were reported to be functionally deaf. Seizure disorders were reported for 45.0% of residents and 19.4% were reported to have cerebral palsy. More than half (52.4%) of all residents were reported to have some form of behavior disorder and 45.7% were reported to have a psychiatric condition. About 47.0% of all residents were reported to have 2 or more of these conditions. In comparison, in 1977, 6.0% of state institution residents were blind, 3.6% were deaf, 32.5% had epilepsy, 19.3% had cerebral palsy, 25.4% were reported to have a behavior disorder and 35.1% to have two or more of these conditions.

Males remained a substantial majority among large state facilities’ residents. Males made up 62.8% of state facility populations in 2002. Males have made up a majority of state facility populations since the first national survey reporting gender statistics in 1904 when 53.1% of state institution residents were male. That proportion has very gradually increased over the years to 57.0% in 1977, 57.4% in 1982, 57.7% in 1987, and 58.5% in 1991.

All State and Non-State Residential Services

Number and Size of Residential Setting

The number of residential settings for persons with ID/DD is growing very rapidly. On June 30, 2002 there were an estimated 125,415 residential settings in which persons with ID/DD received residential services from state operated or state licensed residential service providers (excluding psychiatric facilities, nursing homes and people receiving services while living with family members). Since 1977 the number of settings in which people receive residential services has grown more than eleven-fold. In comparison, on June 30, 1977 there were 11,008 state licensed or state operated residential service settings; on June 30, 1987 there were 33,477; on June 30, 1992 there were 49,479; on June 30, 1995 there were 84,532; and on June 30, 1998 there were 104,765. Of all residential service settings on June 30, 2002, 2,320 were operated by states, with the remaining 123,095 residential settings served by nonstate agencies.

Most residences licensed or operated by states for persons with ID/DD were small and almost all people living in small residences were served by nonstate agencies. Of the 125,415 total residential settings on June 30, 2002, an estimated 124,156 (99.0%) had 15 or fewer residents and 117,823 (94.0%) had 6 or fewer residents. The estimated 122,069 nonstate settings with 15 or fewer residents made up 98.3% of all settings with 15 or fewer residents. The 116,189 nonstate settings with 6 or fewer residents made up virtually all (98.6%) of the settings with 6 or fewer residents.

Most large residences were also operated by nonstate agencies. Nonstate agencies operated 1,026 (81.5%) of the total 1,259 facilities with 16 or more residents. This compares to 80.8% in 1977, 82.7% in 1987 and 85.6% in 1999.

Number of Residents

Between 1977 and 2002, there was a steady increase in the total number of persons with ID/DD receiving residential services. Between 1977 and 2002 the total number of residential service recipients grew 58.5%, from 247,780 to a reported 392,740. Total population increases (both nonstate

and state settings) were limited to places with 15 or fewer residents, the populations of which increased by and estimated 278,391 between 1977 and 2002. Total populations of facilities with 16 or more residents decreased by 133,431 persons between 1977 and 2002. Between 2001 and 2002 residents of settings with 15 or fewer residents increased by an estimated 8,250 persons, while residents of facilities with 16 or more residents decreased by 3,255.

The national average rate of placement in residential settings for persons with ID/DD in 2002 was 136.2 persons per 100,000 of the general population. Twenty-nine states reported residential placement rates at or above the national average, with the highest rate (318.9 per 100,000 state residents) in North Dakota. The lowest placement rate (55.9 per 100,000) was reported by Arizona. Eight states reported placement rates 150% or more of the national average and four states reported placement rates 50% or less of the national average. The national average placement rate of 136.2 in 2002 was higher than the 2001 rate of 136.1 and the 1977 rate of 118.8.

In 2002 about 81.2% of the persons with ID/DD receiving residential services lived in places with 15 or fewer residents, 67.5% lived in places with 6 or fewer residents, and 44.6% lived in places with 3 or fewer residents. On June 30, 2002, residences of 15 or fewer persons housed an estimated 318,815 people (81.2% of all residents). Settings with 6 or fewer residents housed 264,920 residents (67.5% of all residents) and settings with 3 or fewer residents 174,976 (44.6% of all residents). Of the 318,815 persons living in places with 15 or fewer residents, 306,254 (96.1%) lived in settings operated by nonstate agencies. The 259,388 persons living in nonstate settings with 6 or fewer residents made up almost all (97.9%) or the 264,920 people living in places with 6 or fewer residents.

A substantial majority of persons with ID/DD who received residential services from nonstate agencies lived in smaller settings, while a substantial majority of persons who lived in state residences lived in large facilities. On June 30, 2002 nine-tenths (91.1%) of the 336,113 persons receiving residential services from nonstate agencies lived in settings of 15 or fewer residents, and more than three-fourths (77.2%) lived in settings with 6 or fewer

residents. More than three-fourths (77.8%) of the 56,627 persons living in state operated settings were in facilities with 16 or more residents. Of the 73,925 residents of residential settings with 16 or more residents, 44,066 (59.6%) lived in state facilities. In 1977, 74.6% of the 207,356 residents of facilities with 16 or more residents lived in state facilities.

Interstate Variability

Only one state reported a majority of persons with ID/DD receiving residential services lived in facilities of 16 or more residents. On June 30, 2002 more than seven-tenths (70.3%) of the residents of all settings in one state (Mississippi) lived in facilities with 16 or more residents. Nationally, 25.6% of all residential service recipients lived in settings of 16 or more residents.

In more than five-sixths (43) of all states a majority of persons with ID/DD received residential services in settings with 6 or fewer residents. On June 30, 2002 more than half of the residents of all settings in Alaska, Arizona, California, Colorado, Connecticut, Delaware, the District of Columbia, Hawaii, Idaho, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Texas, Utah, Vermont, Washington, West Virginia, Wisconsin, and Wyoming lived in settings with 6 or fewer residents. In 21 states one-half or more of the residents lived in settings of 3 or fewer.

State and Nonstate Residential Settings by Type

Most people receiving residential services receive it in places that provide “congregate care.” Congregate care is provided in settings owned, rented or managed by the residential services provider, or the provider’s agents in which paid staff provide care, supervision, instruction and other support and include, but are not limited to ICFs-MR. An estimated 266,687 persons with ID/DD lived in congregate care settings on June 30, 2002 (67.9% of all residential service recipients). A majority of these persons (189,602 or 71.1%) lived in settings with 15 or fewer residents and over one-half of those 135,571 (50.8%) lived in settings with 6 or fewer residents.

The number of people living in host family/foster care is slowly increasing. An estimated national total of 42,272 persons with ID/DD lived in host family/foster care settings on June 30, 2002. This represents a 3.9% increase from one year earlier. Virtually all (99.96%) host family care residents lived in homes with 6 or fewer residents. Between June 30, 1982 and June 30, 2002 the estimated number of people in host family settings increased from approximately 17,150 to 42,272 (146.5%).

About 22.1% of persons receiving ID/DD residential services live in their “own homes” that they own or lease. An estimated national total of 86,694 persons with ID/DD receiving residential services and supports lived in homes that they owned or leased for themselves. The number of persons living in homes of their own increased 8.0% between June 30, 2001 and June 30, 2002. Between 1993 and 2002 the estimated number of people living in homes of their own nationally increased by 155.8% as the movement toward consumer controlled housing and supported living continued.

The number of people with ID/DD receiving residential services living in settings of 3 or fewer persons continues to increase. An estimated 174,976 (44.6%) were living in homes of 3 or fewer residents in 2002, more than 11 times as many as the 15,705 people in settings of 3 or fewer in 1982. Among 46 states for which these data were available, persons with ID/DD living in settings of 3 or fewer persons ranged from 12.9% to 94.7% of all persons with ID/DD receiving residential services.

Patterns of Change in Residential Service Systems: 1977-2002

The number of residential settings in which people received services increased much faster than the total number of service recipients. Between 1977 and 2002, the total number of residential settings in which people with ID/DD received residential services grew from 11,008 to an estimated 125,415 (1,039.3%), while total service recipients increased by 58.5%, from about 247,780 to an estimated 392,740 individuals.

The nation moved from large facility-centered to community residential services. In 1977, 83.7% of the estimated population of persons with ID/DD receiving residential services lived in residences of

16 or more people. By 2002, an estimated 81.2% lived in community settings of 15 or fewer people, and 67.5% lived in residential settings with 6 or fewer people. Only about 22.1% of residential service recipients lived in homes that they themselves owned or rented.

The role of the state as a residential service provider dramatically declined. In 1977, 62.9% of all residential service recipients lived in state residential settings. By 2002, less than one-sixth (14.4%) of all residential service recipients lived in state residential settings.

States reported a large number of service recipients living in their family homes. In 2002, an estimated 482,479 persons received services in their family homes. This equals 55.1% of all persons receiving ID/DD residential services in or out of their family homes. Recipients of ID/DD family-based services in states ranged from 7.0% to 85.0% of service recipients.

On June 30, 2002, there were an estimated 59,818 persons waiting for residential services. Based on reports of 36 states it was estimated that 59,818 persons not presently receiving ID/DD services outside their family homes are waiting for such services. It would require an estimated 15.2% growth in available residential service capacity to provide residential services to all of the persons currently waiting. The range of growth required to meet present needs ranged from 0.0% to 131.8%.

Medicaid Funded Services

Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR)

The total number of ICFs-MR from 2001 to 2002 increased by 8 facilities. On June 30, 2002 there were 6,623 ICFs-MR nationwide, as compared to 6,615 in 2001. Average ICF-MR size in 2002 was 16.7 residents; this compares with 186 residents in 1977; 74.5 residents in 1982; 37 residents in 1987; 22.5 residents in 1992; and 17.2 residents in 2001.

In 2002, the population of ICFs-MR continued to decrease. From 1982 to 1994 the ICF-MR program was notable for its stability in the number of persons served. On June 30, 1994 there were 142,118

persons living in all ICFs-MR. This compares with 140,684 on June 30, 1982. By June 1999 the total ICF-MR population had decreased to 117,917. The June 2002 population of ICFs-MR was 110,572, a decrease of 3,335 (2.9%) from the previous year.

Populations of large ICFs-MR have continued to decrease steadily. On June 30, 2002 there were 68,811 persons in ICFs-MR of 16 or more residents (62.2% of all ICF-MR residents). This represented a 43.0% decrease from the 120,822 persons in large ICFs-MR in 1987 and a 47.4% decrease from 130,767 large ICF-MR residents in 1982. The 2002 population of large ICFs-MR included 43,530 residents of state ICFs-MR and 25,281 residents in nonstate ICFs-MR. Between June 30, 1988 and June 30, 2002, large state ICF-MR populations decreased 14.3% (from 50,778), while large nonstate ICF-MR populations decreased by 10.5% (from 28,246).

Almost all residents of large state and nonstate residential facilities live in ICFs-MR. In 2002, 92.1% of persons living in all large state and nonstate facilities lived in ICF-MR units, and 98.8% of people living in state facilities of 16 or more residents lived in ICF-MR units.

In 2002, only 4 of 10 ICF-MR residents were living in state facilities. On June 30, 2002, 40.3% of all ICF-MR residents were living in state facilities. This compares with 63.2% on June 30, 1987; 77.2% on June 30, 1982 and 87.5% on June 30, 1977. The decreased concentration of ICF-MR residents in state facilities is associated with the general depopulation of large state ID/DD facilities and the increase in the number of community ICFs-MR. On June 30, 2002 there were 43,530 persons in ICF-MR units of large state ID/DD facilities (39.4% of all ICF-MR residents). This compares with 88,424 persons on June 30, 1987 (61.2% of all ICF-MR residents), and 107,081 persons on June 30, 1982 (76.3% of all ICF-MR residents).

The number of residents of community ICFs-MR decreased slightly in 2002. On June 30, 2002 there were 41,761 persons with ID/DD living in community ICFs-MR with 15 or fewer residents. This represents a slight decrease of 1.1% from June 30, 2001. Community ICFs-MR continued to house many more than the 25,328 persons on June 30, 1987, and the

9,985 persons on June 30, 1982. On June 30, 2002, 46.7% of residents of community ICFs-MR lived in facilities with 6 or fewer residents. Between June 30, 1982 and June 30, 2002 the total number of persons with ID/DD living in ICFs-MR of six or fewer residents increased from 2,572 to 19,497. The number of people living in ICFs-MR of 6 or fewer residents decreased between June 30, 2001 and June 30, 2002 by 407 residents (2.0%).

A relatively small proportion of persons with ID/DD in community settings live in ICF-MR certified residences. Nationally, on June 30, 2002 only 13.1% of the persons in settings with 15 or fewer residents lived in ICFs-MR. Persons living in settings with 7 to 15 residents were far more likely to live in ICFs-MR than persons living in settings of 6 or fewer residents; 22,264 (42.1%) of the 52,914 persons living in settings with 7 to 15 residents lived in ICFs-MR, while only 19,497 (7.5%) of the 260,100 living in settings with 6 or fewer residents lived in ICFs-MR.

In 2002 total ICF-MR expenditures were more than in 2001. In Fiscal Year 2002 total federal and state expenditures for ICF-MR services were 10.7 billion dollars. This was an increase from the 10.2 billion dollars expended in FY 2001. Comparable expenditures were \$8.8 billion dollars in 1992, \$5.6 billion in 1987, \$3.6 billion in 1982 and \$1.1 billion in 1977.

Per resident ICF-MR expenditures in 2002 continued to increase. In 2002 the average expenditure for end of year ICF-MR residents was \$97,190. This compares with the average 2001 per resident expenditure of \$89,858. The average 2002 expenditure was \$95,746, or 132.4%, more than the average per resident expenditure of 13 years earlier. States varied substantially in expenditures per ICF-MR resident, from more than \$120,000 per year in fifteen states to less than \$60,000 per year in 2 states. Total ICF-MR expenditures per person in the general population averaged \$37.27 per year nationally. Two states spent over twice the national average.

Medicaid Home and Community Based Services (HCBS)

Growth in HCBS recipients continues. On June 30, 2002 there were 378,566 persons with ID/DD receiving HCBS, an increase of 15.4% over the

328,159 recipients on June 30, 2001. In the twelve years between June 30, 1990 and 2002, the number of HCBS recipients grew by 338,728 persons (850.3%) from 39,838 HCBS recipients. The number of states with approved applications to provide HCBS increased from 42 to 51. Forty-five states increased their number of HCBS recipients by 1,000 or more between 1990 and 2002.

The number of people receiving HCBS is more than twice the number living in ICFs-MR. On June 30, 2002 the number of HCBS recipients (378,566) was 342.4% of the number living in ICFs-MR. Only eight years earlier on June 30, 1994 the number of ICF-MR residents (142,118) was greater than the number of HCBS recipients (122,075).

The number of people receiving residential services outside the family home with HCBS financing is substantially greater than those receiving residential services in ICFs-MR. Of the 51 states with HCBS programs, 48 were able to report, in whole or part, the residential arrangements of their HCBS recipients. These states reported residential arrangements for 267,893 individuals, 70.8% of 378,566 HCBS recipients on June 30, 2002. More than three-fifths (60.5%) of these HCBS recipients were receiving residential services outside their family home. Applying this statistic to all HCBS recipients on June 30, 2002 yields an estimated 229,032 persons receiving residential services funded by HCBS while living away from the home of their parents or other relatives. This estimated number of HCBS residential service recipients was more than twice the number of ICF-MR residents.

Expenditures for Medicaid HCBS recipients continue to grow and show substantial interstate variability. In Fiscal Year 2002 expenditures for Medicaid HCBS recipients were 13.4 billion dollars for 378,566 recipients, a per end of year recipient average of \$35,298 per year. Expenditures adjusted for average daily HCBS recipients were \$37,816 per person. This represents a 78.0% total or 6.5% average annual increase in per recipient average expenditures between Fiscal Year 1990 (\$21,246) and Fiscal Year 2002. The states with the highest per recipient expenditures in Fiscal Year 2002 were Connecticut (\$67,827) and Delaware (\$64,190). The states with the lowest per recipient expenditures in Fiscal Year 2002 were District of Columbia (\$7,340) and Missis-

sippi (\$12,201).

ICF-MR and HCBS Combined

Growth in the total number of ICF-MR and HCBS recipients has continued at a steady rate. The combined total of 489,138 ICF-MR and HCBS recipients on June 30, 2002 represented a 13.3% average annual increase between June 30, 1992 and June 30, 2002. Between 1992 and 2002 the combined total of ICF-MR and HCBS recipients grew by an average 28,042 persons per year. In comparison, between 1982 and 1987 the combined totals of ICF-MR and HCBS recipients increased at an annual average of about 4,995 persons. Between 1987 and 1992 the combined average annual increase of ICF-MR and HCBS recipients was approximately 8,000 persons. On June 30, 2002, HCBS recipients made up 77.4% of the combined total of 489,138 ICF-MR and HCBS recipients. This compares with just 16.4% fifteen years earlier on June 30, 1987.

On June 30, 2002 ICF-MR and HCBS community service recipients made up more than four-fifths of the combined total of ICF-MR and HCBS recipients. On June 30, 2002 residents of community ICFs-MR (15 or fewer residents) and HCBS recipients made up 85.9% of all ICF-MR and HCBS recipients. That compares with 83.8% on June 30, 2001, 81.9% on June 30, 2000, 80.2 on June 30, 1999; 78.3% on June 30, 1998; 68.6% on June 30, 1995; and 33.0% fourteen years earlier on June 30, 1988. In all states most of the combined ICF-MR and HCBS recipients were receiving community services.

There remains remarkable variation among states in ICF-MR and HCBS utilization rates. On June 30, 2002 there was a national ICF-MR utilization rate of 38.3 ICF-MR residents per 100,000 persons in the United States. The highest individual state ICF-MR utilization rates were 128.6 in District of Columbia and 123.6 in Louisiana. The highest utilization of large ICFs-MR were in Arkansas (50.5), Illinois (51.9), Iowa (50.5), Louisiana (59.6), Mississippi (69.6), and Oklahoma (58.5). State HCBS utilization rates varied from more than twice the national average of 131.3 in five states to less than half of the national average in seven states. On June 30, 2002

nationally there was an average of combined ICF-MR and HCBS recipients of 169.6 per 100,000 of the population. Individual state utilization rates for the combined programs varied from the highest rates in Iowa (285.5), Minnesota (348.4), New York (302.6), North Dakota (416.3), South Dakota (326.4), Vermont (301.0) and Wyoming (323.4) to the lowest rates in Kentucky (65.6) and Nevada (61.0).

Medicaid expenditures are disproportionately greater for persons in ICFs/MR than HCBS recipients. The annual Medicaid expenditures per average daily recipient of ICF-MR services was \$95,746 as compared to \$37,816 per each HCBS recipient. As a result, nationally in Fiscal Year 2002, HCBS recipients made up 77.4% of the total HCBS and ICF-MR recipient population but used only 55.4% of the total Medicaid HCBS and ICF-MR expenditures. In FY 2002 for the fifth consecutive year in the majority of states HCBS expenditures were greater than ICF-MR expenditures.

Differences in state benefits from Medicaid spending continues. Almost any measure of each state's relative benefits from Medicaid funding yields significant interstate differences. Indexing Fiscal Year 2002 federal reimbursements for ICF-MR and HCBS programs in each state by federal income tax paid by residents of each state, 6 states received over twice their relative federal income contributions tax back in benefits, Iowa (\$2.06 in benefits per \$1.00 contributed), Louisiana (\$2.26), Maine (\$2.68), North Dakota (\$3.60), Oklahoma (\$2.05) and West Virginia (\$2.41). By the same measure three states received back less than half their relative contributions (California, Colorado and Nevada).

Nursing Home Residents

The number of persons with ID/DD in Nursing Facilities continues to decrease slowly. On June 30, 2002 there were 34,820 persons with ID/DD in Medicaid Nursing Facilities. This compares with 38,799 on June 30, 1992. Nationwide, in 2002, 8.1% of all persons with ID/DD receiving residential services and 6.6% of all with ID/DD receiving services through Medicaid ICF-MR, HCBS or Nursing Facility programs were in Medicaid Nursing Facilities.