

**TEN QUESTIONS:
ON THE ROLE OF MEDICAID
FOR PERSONS WITH
DEVELOPMENTAL DISABILITIES
IN THE UNITED STATES**

by

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TEN QUESTIONS ON THE ROLE OF MEDICAID FOR PERSONS WITH DEVELOPMENTAL DISABILITIES IN THE UNITED STATES

INTRODUCTION

The Medicaid program is the single most important public sector program in the United States for people with mental retardation and closely related developmental disabilities. It is a particularly important program for individuals receiving long-term care services. This paper is written to promote greater understanding of the significance of the Medicaid program for individuals with developmental disabilities and their families. A second specific purpose of the paper is to assess the potential impact of current federal proposals to reform and/or reduce spending in the Medicaid program.

The paper has three components. An overview of the federal-state Medicaid program is presented in Part I. Part II briefly summarizes historical and current national trends in the provision of long-term care services for persons with developmental disabilities. Particular emphasis is given in this section to the Medicaid program's important role in financing these services. The paper concludes in Part III with an analysis of the potential impact of current federal and state actions to control Medicaid spending for individuals with developmental disabilities.

PART I: OVERVIEW OF THE NATION'S MEDICAID PROGRAM

QUESTION 1: WHAT IS MEDICAID?

Medicaid legislation was enacted in 1965 as Title XIX of the Social Security Act (PL 89-97). Medicaid was designed initially to help low-income elderly persons meet costs of insurance premiums, deductibles, coinsurance payments, and uncovered health care services. Medicaid consolidated earlier federal efforts to assist poor people by extending the Kerr-Mills Medical Assistance to the Aged Act to families with children and to persons

who were blind or disabled. Medicaid has evolved into three separate but related programs: a health insurance program for low income Americans; a long-term care program for the elderly; and a specialized service and long-term care program for individuals with disabilities including developmental disabilities (Congressional Research Service, 1993).

In 2003, Medicaid is serving 50.7 million Americans, 18% of the U.S. population of 281.4 million, and federal-state payments for these beneficiaries totaled \$268.1 billion. Spending consisted of \$152 billion in federal Medicaid reimbursements and \$116 billion in required state matching funds (Centers for Medicare and Medicaid Services, 2002). Medicaid is a means-tested “entitlement” program. It provides a legal right to services for individuals who are eligible because of their age, income, disability, or medical need. In nearly all cases, beneficiaries of cash assistance from Supplemental Security Income (SSI) and Temporary Assistance for Needy Families (TANF) are eligible for Medicaid.

Designed to implement welfare reform, the Personal Responsibility and Work Opportunity Act of 1996 (PL 104-193) established the Temporary Assistance for Needy Families (TANF) block grant. Federal matching funds were made available to states for cash and other assistance to low-income families with children. The TANF welfare reform law repealed Aid to Families with Dependent Children (AFDC) under which states had been required to provide Medicaid coverage for all families receiving AFDC benefits. Now, states are not required to extend Medicaid coverage to all families receiving TANF benefits, but must extend Medicaid to families with children who meet the eligibility criteria that states had in effect under their AFDC programs as of July 16, 1996 (Schneider, Elias, Garfield, Rousseau, and Wachino, 2002).

Medicaid is a Partnership

Medicaid is a *federal-state partnership* predicated on a formal state plan. State governments have great latitude in designing their Medicaid State Plans, so long as they meet minimum federal standards. States vary greatly in administrative practices and in the types and amounts of services individuals receive under their Medicaid programs. Each state also has its own “federal medical assistance percentage” or “FMAP” matching rate based on per capita personal income in the state, with a minimum rate of 50%. The FMAP rate determines the levels of federal and state matching funds. Mississippi currently receives the highest FMAP rate of 77% because it has the lowest per capita personal income. If Mississippi provides \$1 in state Medicaid matching funds, it receives nearly \$4 in federal Medicaid reimbursement. The 13 wealthiest states (CA, CO, CT, DE, IL, MD, MA, MN, NH, NJ, NY, VA, and WA) in federal fiscal year 2004 in terms of per capita personal income have the minimum FMAP rate. Each dollar of state funds in these states is matched by one dollar of federal Medicaid reimbursement.

Medicaid services vary across states in terms of eligibility criteria and levels of payment for services. Most states use federal SSI eligibility for determining Medicaid coverage. However, twelve states were permitted to continue to use financial standards and definitions of disability in effect prior to the enactment of SSI legislation in 1972 (PL 92-603). These are “Section 209(b)” states, after Section 209b of the Social Security Act Amendments of 1972 (PL 92-603). Variations among states in levels of Medicaid payments are evident in the wide range of provider reimbursement rates for privately operated Intermediate Care Facility/Mentally Retarded (ICF/MR) settings serving 15 or fewer individuals. These settings must meet the same federal regulations across the 34

states offering this “optional” Medicaid service, but states’ provider reimbursement rates in 2000 ranged from \$358 per day in Vermont to \$82 in Colorado (Braddock, 2002).

Mandatory versus Optional Services

State Medicaid programs also differ in terms of *mandatory* services that states must provide versus the elected or *optional* services that each state may provide, as specified in its state plan. For example, inpatient hospital, outpatient hospital, Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), and some nursing facility services are mandatory services that are provided by all states. The Home and Community Based Services (HCBS) Waiver, ICF/MR, personal care services, and case management services are optional services the states may choose to provide. Medicaid’s “mandatory” and “optional” services are displayed in *Table 1*. Six optional services are critically important to individuals with developmental disabilities in that they are significant programmatic components of service delivery systems in the states (Braddock, 2002). The six most significant optional services are two health care services (clinic and rehabilitative services), one institutional long-term care service (ICF/MR), and three community-based long-term care services (HCBS Waiver, personal assistance services, and targeted case management). Through these six programs, federal-state Medicaid spending in 2002 for persons with developmental disabilities constituted 77% of the \$34.6 billion in total developmental disabilities long-term care spending in the United States (State of the States, 2003).

The ICF/MR program and the HCBS Waiver are the most important optional services because together they finance the large majority of the costs of long-term care for people with developmental disabilities in the United States. Mandatory Medicaid services are also critical to individuals with developmental disabilities, whether they live with their

TABLE 1
MEDICAID STATUTORY BENEFITS CATEGORIES

MANDATORY ITEMS AND SERVICES	OPTIONAL ITEMS AND SERVICES
Health care	
Physicians' services	Medical care or remedial care furnished by licensed practitioners under state law
Laboratory and x-ray services	Prescribed drugs
Inpatient hospital services	Disagnotic, screening, preventive, and rehabilitative services
Outpatient hospital services	Clinic services
Early and periodic screening, diagnosis, and treatment (EPSDT) services for individuals under 21	Primary care case management services
Family planning services and supplies	Dental services, dentures
Federally-qualified health clinic (FQHC) services	Physical therapy and related services
Rural health clinic (RHC) services	Prosthetic devices, eyeglasses
Nurse midwife services	TB-related services
Certified pediatric and family nurse practitioner services	Other specified medical and remedial care
Long-term care	
<i>Institutional Services</i>	
Nursing facility (NF) services for individuals 21 or over	Inpatient hospital and NF services for individuals 65 or over in an institution for mental diseases (IMD)
	Intermediate care facility for individuals with mental retardation (ICF/MR) services
	Inpatient psychiatric hospital services for individuals under age 21
<i>Home & Community-Based Services</i>	
Home health care services (for individuals entitled to NF care)	Home health care services
	Case management services
	Respiratory care services for ventilator-dependent individuals
	Personal care services
	Private duty nursing services
	Hospice care
	Services furnished under a PACE program
	Home- and community-based services (HCBS waiver, subject to budget neutrality)

Source: D. Braddock, R. Hemp, and M.C. Rizzolo, *State of the States in Developmental Disabilities Project*, University of Colorado Department of Psychiatry, 2003; Compiled from Schneider et al. (2002).

families or in publicly financed residential settings. Medicaid's hospital, outpatient, and physician services provide basic health care services to children and adults with developmental disabilities.

The EPSDT program helps prevent developmental disabilities and ameliorate their consequences. Public Law 101-239, enacted in 1989, required Medicaid coverage of additional EPSDT screenings when a medical problem is suspected, and also expanded Medicaid's coverage of women and children. Coverage of children was expanded up to 133% of the poverty level in this legislation. The Omnibus Budget Reconciliation Act of 1990 (PL 101-508) extended Medicaid coverage to children aged 6 through 18 in families with incomes at or below 100 percent of the federal poverty level (Assistant Secretary for Planning and Evaluation, 2003). The Balanced Budget Act of 1997 (PL 105-33) established, in Title XXI of the Social Security Act, the State Children's Health Insurance Program (SCHIP), a block grant to states for coverage of uninsured low income children otherwise ineligible for Medicaid (Schneider et al., 2002).

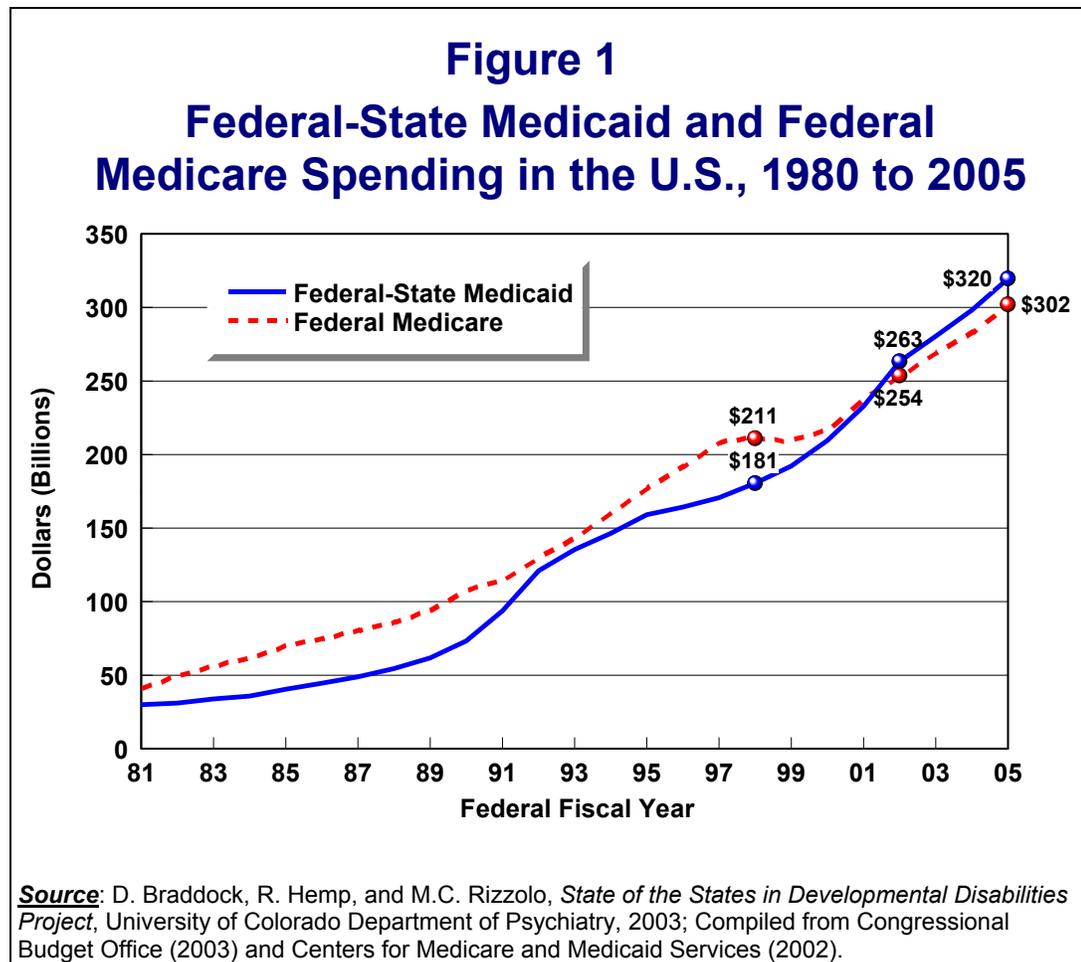
In addition to these expansions of Medicaid health services for children, there have been important Medicaid amendments for individuals with developmental disabilities. These include the ICF/MR statute (PL 92-223) enacted in 1971; the HCBS waiver authority (PL 97-35) enacted in 1981; nursing home reform legislation (PL 100-203) passed in 1987; and the Community Supported Living Arrangement (CSLA) provisions enacted in 1990 (PL 101-508). The Balanced Budget Act of 1997 (PL 105-33), in addition to the establishment of the State Children's Health Insurance Program, extended HCBS Waiver coverage for supported employment services for individuals with developmental disabilities.

The Ticket to Work and Work Incentives Improvement Act of 1999 (PL 106-170) allowed states to provide Medicaid health care to working persons with disabilities with incomes above 250 percent of the federal poverty level. Finally, two additional pieces of Medicaid legislation have had important budgetary impact on all Medicaid services and therefore on people with developmental disabilities. These are the Emergency Supplemental Appropriations for FY 1999 legislation (PL 106-31) that transferred the federal share of settlement funds from national tobacco litigation to states, and the Medicare, Medicaid, and SCHIP Benefits Improvement and Protection Act of 2000 (PL 106-554) that increased state-specific ceilings on the amount of payment allowable to Disproportionate Share Hospitals (DSH). Disproportionate Share Hospital payments, in addition to regular Medicaid payments, are made by a state's Medicaid program to acute care or mental hospitals that the state designates as serving a "disproportionate share" of low-income or uninsured patients. Public Law 106-554 also directed the HHS Secretary to issue regulations closing the "upper payment limit" (UPL) loophole, thereby restricting the amount of Medicaid reimbursement for payments a state may make to hospitals, nursing facilities, other providers, and managed care plans.

Currently, the Bush Administration's "State Health Care Partnership Allotments Plan" (U.S. Government Printing Office, 2003) proposes certain Medicaid long-term care reforms, and reduced Medicaid spending projections after 2010.

Medicaid Compared to Medicare

The Medicare program, like Medicaid, is an important program for persons with developmental disabilities. In 2000, an estimated 461 thousand Medicare beneficiaries with developmental disabilities received \$2.2 billion in federal Medicare benefits. Medicare



served a total of 38.7 million Americans, including 33.6 million senior citizens and 5.1 million beneficiaries with disabilities under age 65 (Social Security Administration, 2002). Federal-state Medicaid spending in the U.S. surpassed federal Medicare spending in 2002 (*Figure 1*). That year, federal-state Medicaid spending totaled \$263 billion compared to \$254 billion for federal Medicare benefits. The Congressional Budget Office (2003) projects Medicaid and Medicare spending to be \$320 and \$302 billion, respectively, in 2005.

The Social Security Act Amendments of 1972 (PL 92-603) authorized Medicare coverage, after a 24-month waiting period, for adult Social Security beneficiaries with developmental disabilities. Individuals with disabilities can be “dually eligible” for

Medicaid and Medicare, and can use Medicaid benefits to pay Medicare premiums and co-payments. Medicaid is a federal-state program. Medicare, however, is administered and funded solely by the federal government, primarily financed through a trust fund consisting of employees' taxes and employers' contributions.

Medicare's hospital insurance program (Part A) covers short-term inpatient hospitalization, some related short-term nursing home care and home health care. Supplementary medical insurance under Medicare Part B pays for physicians' services, outpatient services, certain medical supplies, and durable medical equipment. Medicare Part B is a voluntary program financed by federal appropriations and by premiums paid by beneficiaries. Dually-eligible Medicaid and Medicare beneficiaries, including those with disabilities, may have some or all of their Medicare premiums paid for by Medicaid.

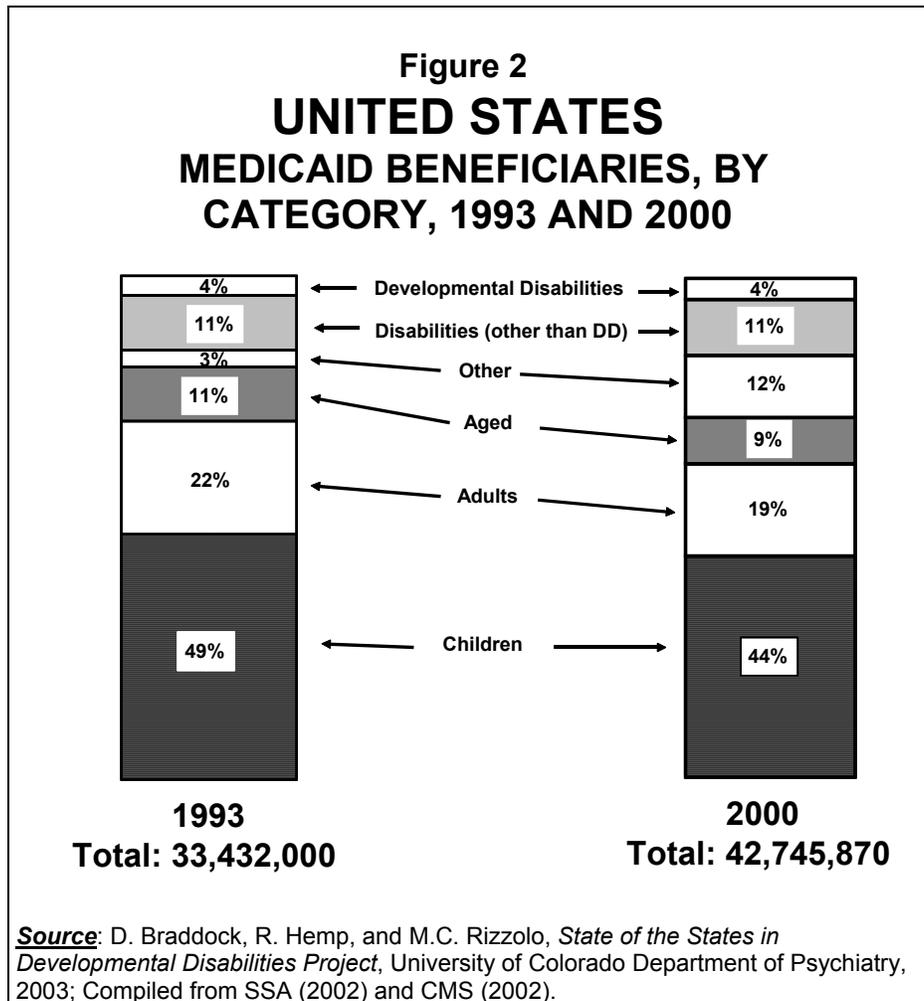
QUESTION 2: WHO ARE BENEFICIARIES OF MEDICAID SERVICES?

The number of Medicaid beneficiaries has increased 28% from 1993 to 2000, four times the 7% rate of growth in the U.S. population during that same period. This beneficiary growth is attributable to a series of Medicaid amendments referenced above that expanded Medicaid services to large numbers of low-income pregnant women, children in low-income working families, people with disabilities (particularly in terms of Medicaid coverage through transition to work) and the elderly. In 2000, 42.7 million Americans received Medicaid-funded programs and services (*Figure 2*). Sixty-three percent of Medicaid's beneficiaries were adults and children.

The number of individuals with all types of disabilities receiving Medicaid services increased from 4.9 million in 1993 to 6.6 million in 2000 and beneficiaries with developmental disabilities increased from 1.3 million to 1.8 million. However, the

proportion of Medicaid beneficiaries with disabilities from 1993 to 2000 remained constant at 15% (**Figure 2**).

It should be noted that the growth from 3% to 12% in “other” Medicaid beneficiaries and the totals for 2000 depicted in **Figure 2** are in part a statistical artifact of the change in the CMS (2002) method of counting Medicaid managed care beneficiaries. Beginning in 1998, Medicaid beneficiaries included those for whom a capitation payment was made. This CMS definitional change between 1997 and 1998 resulted in a relatively large increase of approximately six million beneficiaries, compared to annual increments of approximately two million Medicaid beneficiaries during 1996-97 and 1998-00.



**Table 2:
MEDICAID BENEFICIARIES IN THE UNITED STATES, 2000**

COLUMN # *	Medicaid Beneficiaries by Category					Long Term Care by Category for Persons with DD			
	1	2	3	4	5	6	7	8	9
States	Total Medicaid Beneficiaries	Blind/Disabled Medicaid Beneficiaries	Medicaid Beneficiaries with DD	Total DD % of Blind/Disabled	DD Beneficiaries with Basic Health Care Only	TOTAL, DD Long Term Care Beneficiaries	Nursing Facilities	Public & Private ICFs/MR	HCBS Waiver
Alabama	619,480	161,483	52,966	32.8%	47,059	5,907	930	640	4,337
Alaska	96,432	10,007	1,871	18.7%	1,184	687	6	0	681
Arizona	681,258	92,876	22,383	24.1%	11,268	11,116	57	243	10,816
Arkansas	489,325	99,073	34,775	35.1%	30,105	4,670	867	1,791	2,012
California	7,915,450	899,804	161,965	18.0%	122,153	39,812	1,409	10,170	28,233
Colorado	380,964	61,354	13,682	22.3%	7,450	6,232	270	163	5,799
Connecticut	419,890	53,566	11,785	22.0%	5,301	6,484	378	1,323	4,783
Delaware	115,267	14,734	4,288	29.1%	3,449	839	34	316	489
Dist Of Columbia	138,677	24,109	6,027	25.0%	5,175	852	36	816	0
Florida	2,360,417	416,433	102,443	24.6%	78,234	24,209	191	3,576	20,442
Georgia	1,289,795	216,177	69,609	32.2%	62,698	6,911	1,700	1,599	3,612
Hawaii	203,763	20,367	3,910	19.2%	2,613	1,297	97	111	1,089
Idaho	131,077	21,761	5,875	27.0%	4,602	1,273	28	592	653
Illinois	1,516,082	248,953	75,931	30.5%	56,982	18,949	1,267	10,282	7,400
Indiana	704,624	89,712	33,552	37.4%	24,142	9,410	1,933	5,408	2,069
Iowa	313,648	52,253	17,662	33.8%	10,345	7,317	536	2,190	4,591
Kansas	262,557	46,068	14,650	31.8%	8,285	6,365	13	852	5,500
Kentucky	770,536	193,976	59,163	30.5%	56,203	2,960	744	1,016	1,200
Louisiana	761,248	148,011	53,136	35.9%	43,024	10,112	1,109	5,553	3,450
Maine	191,624	44,637	10,400	23.3%	8,130	2,270	145	285	1,840
Maryland	664,576	105,470	29,953	28.4%	24,302	5,651	121	548	4,982
Massachusetts	1,047,440	216,590	34,221	15.8%	20,069	14,152	1,499	1,293	11,360
Michigan	1,351,650	263,769	80,713	30.6%	71,325	9,388	838	250	8,300
Minnesota	559,463	77,576	20,402	26.3%	9,289	11,113	491	2,933	7,689
Mississippi	605,077	136,572	44,249	32.4%	39,969	4,280	900	2,532	848
Missouri	890,318	123,262	40,060	32.5%	29,840	10,220	830	1,615	7,775
Montana	103,821	16,059	4,111	25.6%	2,543	1,568	162	130	1,276
Nebraska	229,038	27,105	8,592	31.7%	5,518	3,074	115	639	2,320
Nevada	138,069	21,875	4,616	21.1%	3,371	1,245	40	255	950
New Hampshire	96,935	12,577	3,157	25.1%	431	2,726	64	24	2,638
New Jersey	822,369	144,866	32,740	22.6%	21,624	11,116	593	3,629	6,894
New Mexico	375,585	46,256	10,084	21.8%	7,557	2,527	94	273	2,160
New York	3,419,893	318,787	65,989	20.7%	13,377	52,612	3,497	10,419	38,696
North Carolina	1,208,789	202,883	73,241	36.1%	62,592	10,649	397	4,517	5,735
North Dakota	60,864	8,475	2,924	34.5%	211	2,713	184	606	1,923
Ohio	1,304,886	243,978	83,928	34.4%	68,214	15,714	2,430	7,691	5,593
Oklahoma	507,059	66,127	21,954	33.2%	15,449	6,505	1,210	2,019	3,276
Oregon	542,392	60,209	13,487	22.4%	7,344	6,143	180	105	5,858
Pennsylvania	1,492,352	322,832	91,361	28.3%	68,124	23,237	2,350	4,944	15,943
Rhode Island	178,859	31,044	7,575	24.4%	4,899	2,676	162	43	2,471
South Carolina	685,104	109,329	36,953	33.8%	30,155	6,798	121	2,188	4,489
South Dakota	101,951	15,793	4,517	28.6%	2,122	2,395	177	230	1,988
Tennessee	1,550,955	308,524	103,664	33.6%	96,883	6,781	892	1,571	4,318
Texas	2,602,616	309,208	78,230	25.3%	57,147	21,083	2,919	13,024	5,140
Utah	224,268	24,450	7,262	29.7%	3,158	4,104	203	754	3,147
Vermont	138,862	16,986	3,958	23.3%	2,185	1,773	42	12	1,719
Virginia	627,214	117,939	39,156	33.2%	31,221	7,935	1,272	1,965	4,698
Washington	895,279	112,024	24,197	21.6%	11,779	12,418	659	1,229	10,530
West Virginia	335,014	78,408	29,246	37.3%	26,783	2,463	40	513	1,910
Wisconsin	576,636	120,819	38,300	31.7%	26,129	12,171	471	2,835	8,865
Wyoming	46,422	7,122	1,930	27.1%	541	1,389	40	123	1,226
United States	42,745,870	6,582,268	1,796,842	27.3%	1,352,552	444,290	34,743	115,835	293,713

***COLUMN NOTES**

1. Total Medicaid Beneficiaries: Centers for Medicare and Medicaid Services (CMS) (2002).
2. Total Blind/Disabled Medicaid Beneficiaries: CMS (2002).
3. Medicaid Beneficiaries with DD: Estimated from Social Security Administration data (SSA, 2002).
4. Total DD % of Blind/Disabled: (Column 3 divided by Column 2).
5. DD Beneficiaries With Basic Health Care Only: Estimated by subtracting long term support totals (Column 6) from total DD Medicaid beneficiaries (Column 3).
6. DD Long Term Care Beneficiaries: Totals and category breakdowns from Braddock (2002).
- 7-9. Subcategories of Column 6, TOTAL.

Source: D. Braddock, R. Hemp, and M.C. Rizzolo, *State of the States in Developmental Disabilities Project*, University of Colorado Department of Psychiatry, 2003.

In 2000, 1.8 million persons with developmental disabilities received Medicaid services (*Table 2*, Column 3). This estimate stems from a categorical construction of “developmental disabilities” that is similar to the definition used by the ICF/MR program and by most state mental retardation and developmental disabilities agencies. It includes individuals with mental retardation and congenital anomalies receiving SSI or qualifying for Medicaid under other assistance categories in fiscal year 2000 (SSA, 2002).

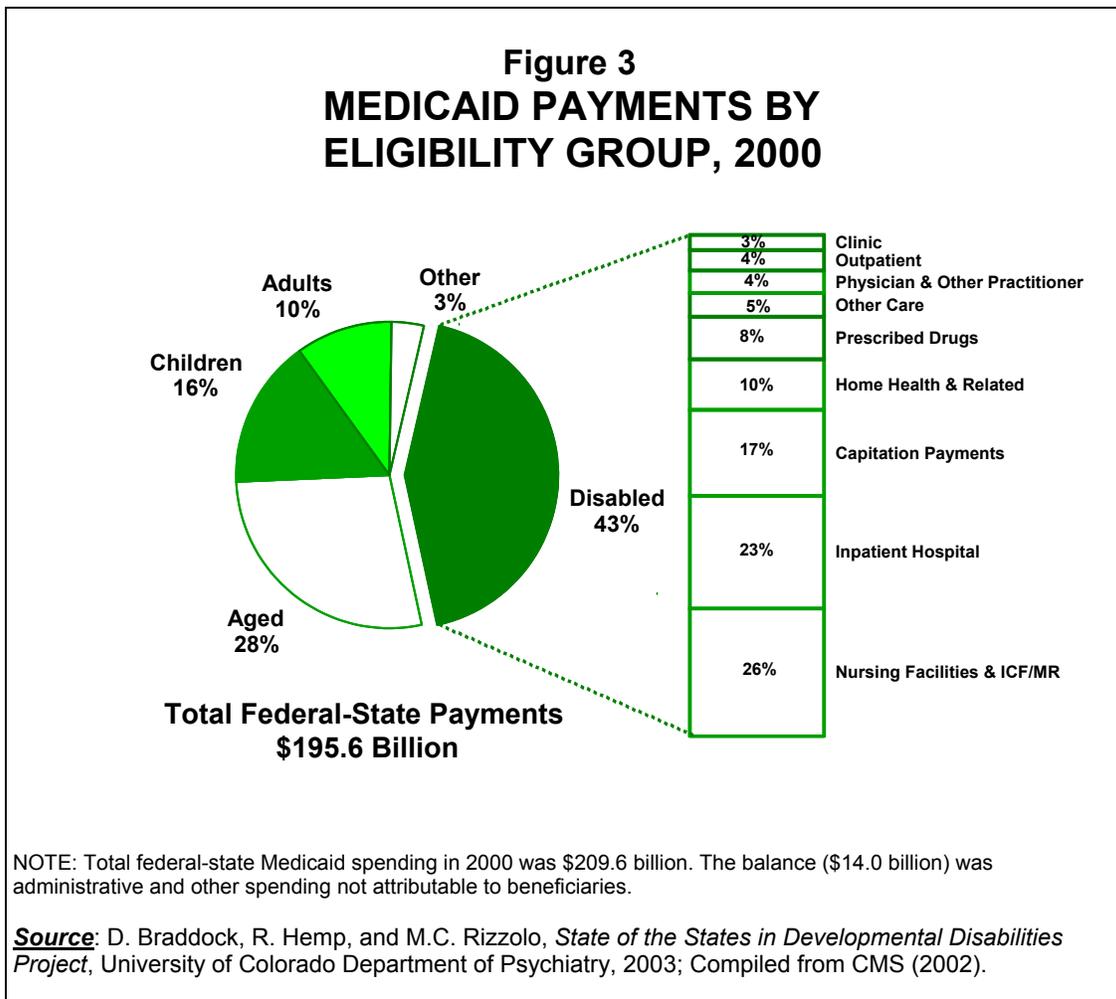
The 1.8 million figure includes 444,290 beneficiaries with developmental disabilities (*Table 2*, Column 6) who received Medicaid financed long term care services in public or private ICFs/MR (i.e., state institutions, private ICFs/MR for 16 or more persons and for 15 or fewer persons, and public ICFs/MR for 15 or fewer persons), in non-specialized nursing facilities, and in HCBS Waiver services (Braddock, 2002). In addition, an estimated 1.35 million Medicaid beneficiaries with developmental disabilities (*Table 2*, Column 5) received basic health care including acute care hospital, outpatient, physician, medication and other health services. These individuals lived with their families, in their own homes, in other homes, or in state or locally funded residential settings and were therefore not receiving Medicaid financed long-term care services.

About two-thirds of beneficiaries with developmental disabilities qualified for Medicaid services because of their SSI eligibility. However, individuals with developmental disabilities might also be eligible for Medicaid as TANF (formerly AFDC) beneficiaries, on the basis of defined “medical need,” and as a Qualified Medicare Beneficiary (PL 99-509). Other laws expanding eligibility were the Omnibus Budget Reconciliation Act of 1986 (PL 99-509), the Medicare Catastrophic Coverage Act of 1988, PL 100-360 and the Omnibus Budget Reconciliation Act of 1989 (PL 101-239).

QUESTION 3: WHAT ARE THE COSTS OF THE MEDICAID PROGRAM AND TO WHAT EXTENT HAVE THEY BEEN INCREASING?

Federal-state Medicaid long-term spending for individuals with developmental disabilities in 2002 totaled \$26.7 billion, consisting of ICF/MR services (\$11.0 billion); HCBS waiver services (\$12.8 billion); and Medicaid support for targeted case management, personal assistance, and clinic and rehabilitative services options (\$2.9 billion) (State of the States, 2003).

In 2000, \$22.0 billion in DD long-term care Medicaid spending constituted 26% of total disability Medicaid spending of \$84.1 billion, and 11% of the total federal-state Medicaid spending in 2000 (\$195.6 billion). Federal-state Medicaid spending by eligibility



group in 2000 is illustrated in *Figure 3* (CMS, 2002). Federal-state long-term care Medicaid payments for individuals with DD constituted 9% of total Medicaid, \$125 billion, in 1993 (Braddock & Hemp, 1996).

Analysis of the components of Medicaid costs must focus on growth (or decline) in the number of beneficiaries and cost per beneficiary, and other Medicaid costs (e.g., DSH). Schneider et al. (2002) discussed the components of Medicaid spending growth in five time periods spanning 1965-98. In the eight years from 1965 to 1972, as the newly authorized Medicaid program was implemented, federal outlays increased an average 53% per year. In the second eight-year period, 1973 to 1980, federal Medicaid outlays grew 15% per year. Key events during that period were the initiation of financing for ICFs/MR and for inpatient psychiatric hospital services for individuals under age 21, and implementation of the SSI program.

In the third period of Medicaid spending growth, a nine-year span from 1981 to 1989, a domestic policy struggle between the Reagan Administration and Congress included debate about how best to control Medicaid costs, and eight separate budget bills addressed Medicaid spending. For example, the Home and Community Based Services (HCBS) Waiver (PL 97-35) was a key administration Medicaid cost-cutting strategy and disability advocates also promoted the Waiver as a long-awaited, flexible Medicaid funding stream for expanded community service options (The Arc, 1989; Nelis and Ward, 1995; Taylor, 1992). Medicaid spending grew 11% per year during 1981-89.

The fourth period considered by Schneider et al. (2002), just three years, 1990-92, saw Medicaid spending grow 28% per year--largely attributable to a 263% increase in DSH spending over that brief period. There was also substantial growth in ICF/MR spending.

The final period considered by Schneider et al., the six-year span from 1993 to 1998, was characterized by federal efforts to curtail DSH spending, the passage of welfare reform legislation that repealed the AFDC link to Medicaid, repeal of the “Boren amendment” that from 1980-97 had required states to pay “reasonable and adequate” hospital and nursing facility rates, and a provision for states to require that most Medicaid beneficiaries enroll in managed care organizations.

The 1993-98 period also included the 104th Congress’ unsuccessful “Contract with America” proposals in 1995 to block grant Medicaid and thereby reduce future Medicaid spending growth (Braddock & Hemp, 1996). Growth during 1993-98 was 11% per year, but this “masks a substantial slow-down in the growth rate between 1995 and 1998 to an average of 3.7 percent...[that] in part reflects declines in DSH payments, declines in enrollment of adults and children resulting from implementation of the 1996 welfare legislation, and a strong economy” (Schneider et al., 2002, p. 92).

Most recently, in the four years from 1999 to 2002, Medicaid spending grew an average 10% per year, reversing the temporary spending decline of the three previous years. Beginning in the first quarter of 2001, increased unemployment, declining state and local tax revenues, and state budget shortfalls provided the first signs of the state economic problems that are now pressuring Medicaid spending (National Conference of State Legislatures, 2002; Zandi, 2001). Between 1993 and 2000, federal-state Medicaid payments per beneficiary increased 50%, from \$3,051 to \$4,576 (CMS, 2002). Across the same seven-year period, the payment for Medicaid beneficiaries with disabilities expanded 65%, from \$7,729 to \$12,777 (Braddock & Hemp, 1996; CMS, 2002; SSA, 2002).

Ku and Broaddus (2003) examined the prospect for rising Medicaid expenditures in 2003 and 2004. Federal-state Medicaid spending grew from \$263.4 billion in 2002 to a projected \$298.2 billion in 2004 (6% per year). Sixty-five percent of the projected 2002-04 spending growth is due to higher costs for the current caseload, the increased expense of prescription drugs and medical technology, and fewer savings from Medicaid managed care. The second component, 43%, is attributable to increased enrollment, primarily, of beneficiaries who are aged and/or have disabilities. There is actually a projected decline in the enrollment of children and non-elderly adults, although this might reverse if the nation's economic problems continue. The third component, -8%, is due to lower DSH payments and the curtailment of hospital and nursing facility payment rates (regulating the "upper payment limit").

Medicaid proved again in recent years its capacity to serve as the safety net for working families who are unemployed and who lose private health insurance in an economic downturn. In a nation that has no universal health care system and that is facing serious demographic and economic pressures, such a safety net continues to be critically important. "By design, Medicaid is counter-cyclical: as unemployment rises and incomes drop in an economic downturn, more people become eligible for Medicaid" (Smith et al., 2003, p. 4).

PART II: OVERVIEW OF DEVELOPMENTAL DISABILITIES SERVICES IN THE U.S. AND THE CENTRALITY OF MEDICAID

QUESTION 4. WHAT ARE THE DOMINANT TRENDS IN LONG-TERM CARE SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES?

State-operated long-term care institutions for individuals with developmental disabilities were initially developed in the eastern U.S. in the mid-19th Century (Howe,

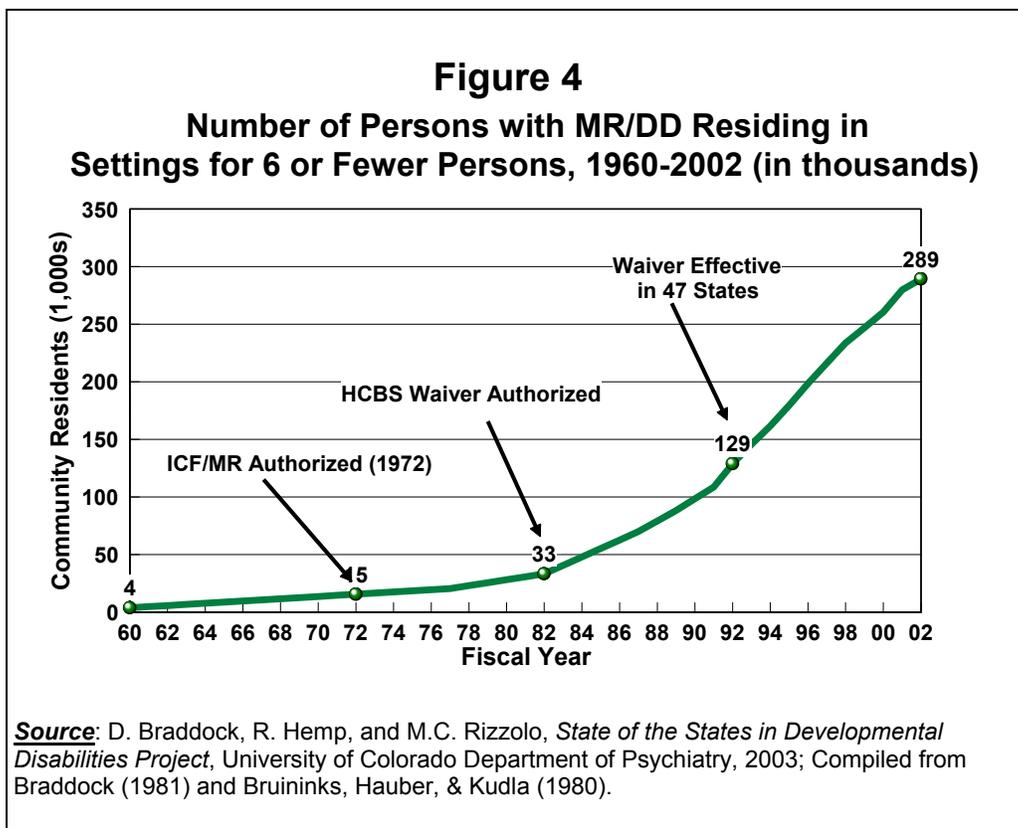
1848). They were designed to provide a temporary residence for individuals who, after a period of education and training, would return to community life. The initial success of the first few facilities encouraged other states to open additional facilities. Unfortunately, as the country industrialized and urbanized, state facilities expanded much faster than their capacity to provide appropriate training and educational services on an individualized basis (Wolfensberger, 1969).

By 1940, more than 100,000 persons with mental retardation were institutionalized across the country (Lakin, 1979). Most residents received minimal custodial care and the trend toward custodial care and “warehousing” of persons with mental retardation accelerated after the Second World War and throughout the 1950s. Media exposés about deficient conditions were commonplace, yet inadequate conditions persisted (Blatt & Kaplan, 1974). Few alternative services were developed in community settings until the 1970s. Class action litigation then helped stimulate the states to act to develop alternative services in the community (Braddock & Fujiura, 1991; Herr, 1983).

In 1967, the nation’s institutional census peaked at 194,650 individuals in 165 state mental retardation facilities (U.S. Department of Health, Education, and Welfare, 1972). Since 1968, however, the number of individuals with developmental disabilities served in these large state facilities has declined between three and six percent each year for 35 consecutive years. By 2000, the residential census of the nation’s state facilities had fallen to 47,374 persons (Braddock, 2002). Most former institutional residents were relocated to community settings including group homes, supervised apartments and supported living arrangements.

On a national basis, 37 states have closed 125 state developmental disabilities institutions since 1970. Alaska, Hawaii, Maine, Minnesota, New Hampshire, New Mexico, Vermont, Rhode Island, West Virginia, and the District of Columbia currently operate residential care service delivery systems entirely in the community. No state institutions remain in these states (Braddock, 2002). The State of Michigan currently has fewer than 200 persons remaining in its state-operated facilities, down from 11,991 residents in such settings in 1962 (U.S. Department of Health, Education, and Welfare, 1965).

The rapid growth of numbers of individuals served in community residential settings in the United States is illustrated in *Figure 4*, which charts the growth of group homes, supervised apartments, and supported living settings that serve six or fewer individuals per setting. The total number of individuals served grew from an estimated 3,727 in 1960 to 289,326 in 2002.



By 1992, 47 states (including New York in 1991) had begun to finance HCBS Waiver services. From 1992 to 2002 there was more than a two-fold increase in the proportion of individuals with developmental disabilities in community-based settings for six or fewer persons, from 36% to 64% of all persons in long-term care settings.

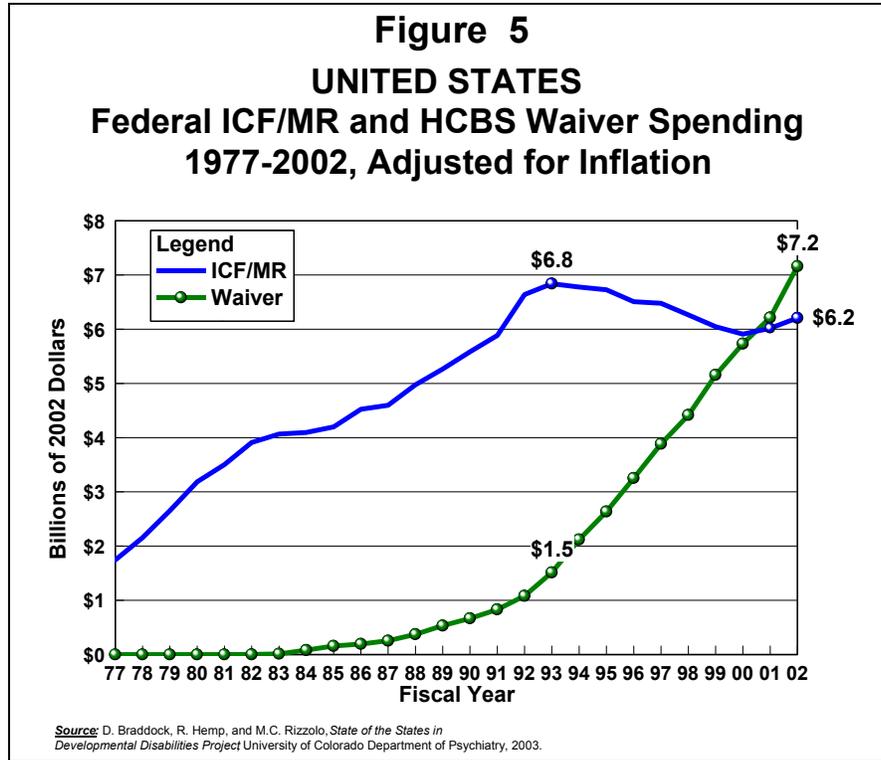
QUESTION 5: WHAT IS MEDICAID'S ROLE IN FINANCING DEVELOPMENTAL DISABILITIES SERVICES?

The Medicaid ICF/MR and Waiver programs have been central to the exponential growth of family-scale and individualized community residential services in the past two decades. Medicaid spending for developmental disabilities residential services was initiated in 1971, when the ICF/MR program supported placements in state institutional settings. By 2002, federal-state ICF/MR funding constituted 100% of institutional spending in those 42 states that still operated public institutions. In 2002, 65% of community services spending in the U.S. derived from the Medicaid program.

Institutional and community developmental disabilities long-term care spending totaled \$34.6 billion in 2002. That year, the combined \$26.7 billion in federal-state Medicaid spending from the ICF/MR program, the HCBS Waiver, targeted case management, personal care, and from clinic and rehabilitative services constituted 77% of total developmental disabilities long-term care spending (State of the States, 2003).

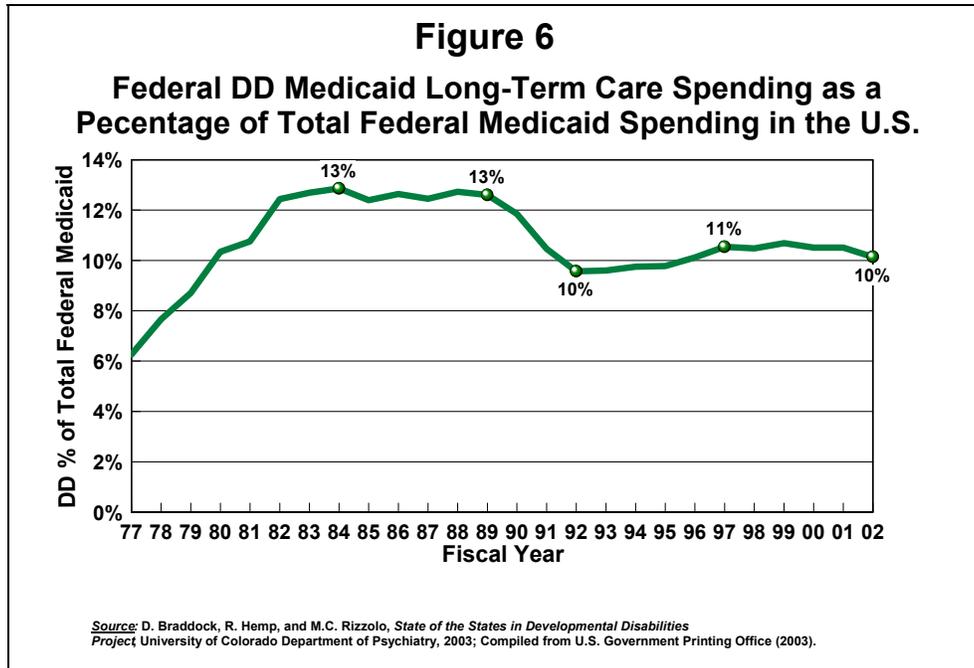
The Home and Community Based Services (HCBS) Waiver

The HCBS Waiver has now emerged as the principal Medicaid program underwriting DD long-term care, surpassing Medicaid ICF/MR spending in the states in 2001 (*Figure 5*). The Waiver provides federal reimbursement for a wide array of community services and supports. These include habilitation training, respite care and other



family support, case management, supported employment, supported living, various professional therapies, assistive technology, behavior management, and a number of other types of assistance in homelike, community-based environments. The Medicaid Waiver, unlike the ICF/MR program, is a financing vehicle and not a distinct, standardized program.

In 2002, the average institutional ICF/MR cost \$130,761 per resident per year, contrasted with an annual Waiver cost per participant of \$31,908. In the 20 states in which federal-state Waiver spending constituted 50% or more of total DD long-term care spending, Waiver costs do not exceed \$70,000 per participant, and in most states ranged from \$35,000 to 40,000 per participant--substantially below the institutional ICF/MR cost of \$130,761.



One significant consequence of the rapidly increasing use of the HCBS Waiver to finance developmental disabilities long-term care is illustrated in *Figure 6*. The proportion of total Medicaid spending devoted to long-term care for persons with developmental disabilities has declined from 13% during 1982-89, to between 10% and 11% annually during the past decade. This declining DD long-term care proportion of total Medicaid spending is largely because the HCBS Waiver in most states has now replaced the ICF/MR program as the financial base for developmental disabilities long-term care services.

The Problem of Low Wages and The Recruitment and Retention of Direct Support Staff

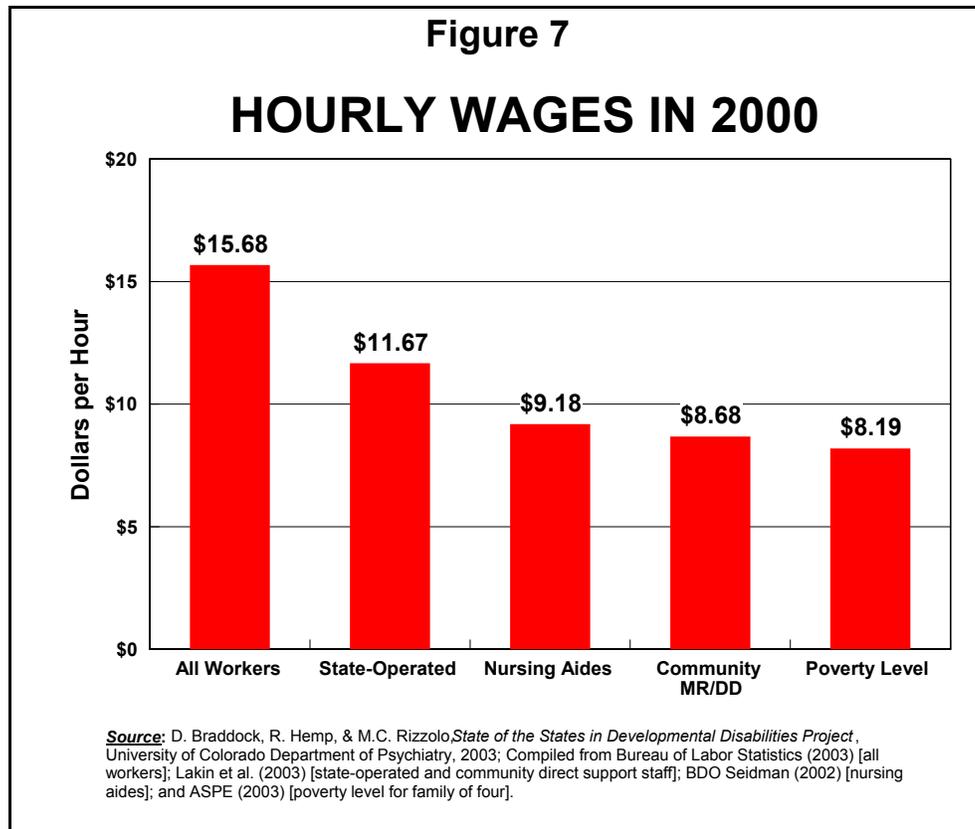
There are serious problems on a nationwide basis with the recruitment and retention of direct support staff in community Medicaid programs (The Arc, 2002). Turnover of direct support staff and the inability to recruit staff are detrimental to the quality of developmental disabilities long-term care programs. Turnover means that persons with disabilities experience a steady withdrawal of the support staff upon whom they depend for

nurturing, consistency, understanding, and appropriate habilitation programs (Lakin, 1988). Employee turnover affects all organizations, but is magnified in human service organizations.

Adequate wages are a major factor in recruiting and retaining qualified staff. Braddock and Mitchell (1992) found, in a large nationwide sample of providers, that starting and average wages (adjusted for states' differing costs of living) were correlated significantly with turnover in community residential programs. Lower wages led to higher turnover. Similar results on the relationship of low wages and turnover were also reported by Lakin and Bruininks (1981), Minnesota Department of Employee Relations (1989), Pivrotto & Bothamley (1986), and Larson, Lakin, & Bruininks (1998).

In a recent national study, BDO Seidman (2002) noted three general economic constraints in the recruitment and retention of developmental disabilities direct care staff: 1) rapidly increasing health insurance costs; 2) growing demand in competing service industries; and 3) the advantage that private sector "supply and demand" employers have over publicly funded human service systems, that unlike the private sector are restricted by fixed appropriations. Fixed appropriations can be used as a means of legislative control over total costs, thereby suppressing staff wages and benefits that constitute 60-70% of DD community program budgets. In contrast, for state-operated services such as state institutions, salary increases are typically tied to the cost of living, they increase annually, and they rise in relation to employee length of time on the job. Because of the large buying power of states, state employee fringe benefits are usually much more generous than those for community direct support staff (e.g. Braddock & Mitchell, 1992).

Direct support staff wages in privately operated community-based long-term care programs are well below the wages of all workers covered by unemployment insurance (Bureau of Labor Statistics, 2003). They also fall below wages for state-operated direct care (Lakin, Polister, and Prouty, 2003), somewhat below nursing aides (BDO Seidman, 2002), and closely approximate the 2000 poverty level for a family of four (Assistant Secretary for Planning and Evaluation, 2003) (*Figure 7*). The Bureau of Labor Statistics (2001) projects a 63% increase in demand for developmental disabilities direct support staff through the year 2010. This is more than twice the projected job demand increase for nursing aides, fast food workers, and all occupations. Medicaid funding for community services, including HCBS Waiver funds, is the key financial resource available to the states to address the growing problem of recruiting and retaining qualified direct support staff. Cutbacks in Medicaid funding will therefore have the effect of reducing wage growth for



direct support staff and thereby jeopardize the quality of care provided through significant increases in employee turnover and difficulty in recruitment.

Increasing Relevance of Assistive Technology

The Assistive Technology Acts of 1988 and 1998 (PL 105-394) defined *assistive technology device* as “any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.” Technology is benefiting people with developmental disabilities in long-term care through enhancing activities of daily living and in promoting health and wellness, employment, and community integration (Rizzolo, Bell, Braddock, Hewitt, and Brown, in press). “Assisted care technology systems” are currently being developed for use in “smart houses.” Such systems combine tracking technology, environmental automation, and ubiquitous computing to promote independence and monitor health status in real time (Elite Care, 2002; Pentland, 1996). This technology may prove to be useful in complementing the activities of direct support staff in developmental disabilities and in other long-term care settings.

Medicaid is an important source of financing for assistive technology devices and services (Allen, 1998; Kemp, Hourcade, and Parette, 2001; Wallace, 1995). Medicaid’s category of durable medical equipment can fund medically necessary devices, and such funding may also be available through Medicaid’s inpatient hospital care program and the HCBS Waiver (Wallace, 1995). Typical areas funded by these Medicaid programs include aids for daily living, prostheses and orthoses, aids for vision and hearing impairments, wheelchairs and other mobility aids, augmentative communication and assistive technology services including occupational, physical and speech therapies and equipment fabrication.

Medicaid “optional” programs including rehabilitative services and physical therapy (see *Table 1*) have been accessed to finance augmentative communication, mobility, and other assistive technology devices. In addition to inpatient hospital services, other “mandatory” Medicaid services that can finance assistive technology include Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) and home health (Kemp et al., 2002). As noted, the HCBS Waiver can finance assistive technology, and there is a specific “assistive technology” service available among the list of potential Waiver services. The support role of technology for people with developmental disabilities is rapidly increasing with the development of new technologies pertinent to cognitive and developmental disabilities. It is therefore critically important to enhance financial support for such technologies through the Medicaid program.

QUESTION 6: IS THE DEMAND FOR LONG-TERM CARE SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES INCREASING?

The demand for MR/DD long-term care is increasing steadily, and at a rapid rate. Despite the increase in community residential services nationally, thousands of individuals await services because they are aging out of special education services where the mandates for funding typically terminate at age 21, are inappropriately placed in public or private institutions or nursing facilities, or live at home with aging caregivers.

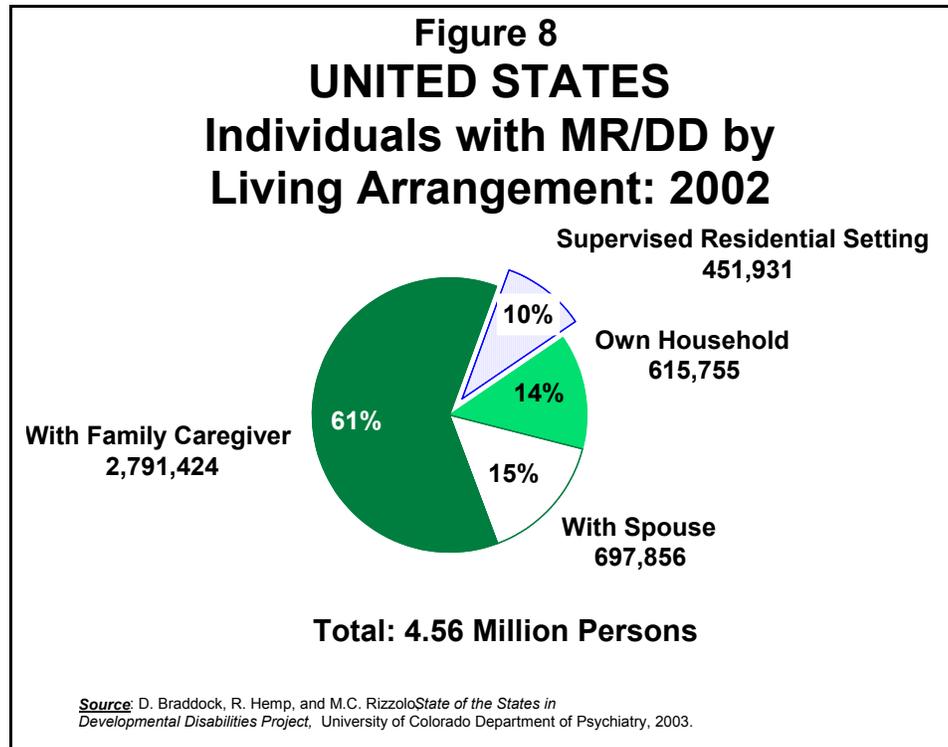
Aging Out of Special Education. Youth with mental retardation and related developmental disabilities age out of, or otherwise exit, special education services and many of these individuals will require community residential services. In school year 1998-99, 70,129 students with mental retardation and closely related developmental disabilities graduated with a diploma, received a certificate, reached the maximum age (21 years) for special education, or were otherwise no longer receiving special education (U.S.

Department of Education, 2001). This number included 61,054 students with mental retardation, 7,526 students with multiple disabilities, and 1,549 students with autism.

Public and Private Institutions. In 2002, 107,965 individuals with mental retardation/developmental disabilities resided in state institutions, nursing facilities, and other private facilities for 16 or more persons (State of the States, 2003). Most states have made a significant effort to find alternative community services for individuals with mental retardation and related conditions in nursing facilities (Mitchell and Braddock, 1990) and have downsized and closed numerous public institutions and private 16+ settings (Braddock, 2002).

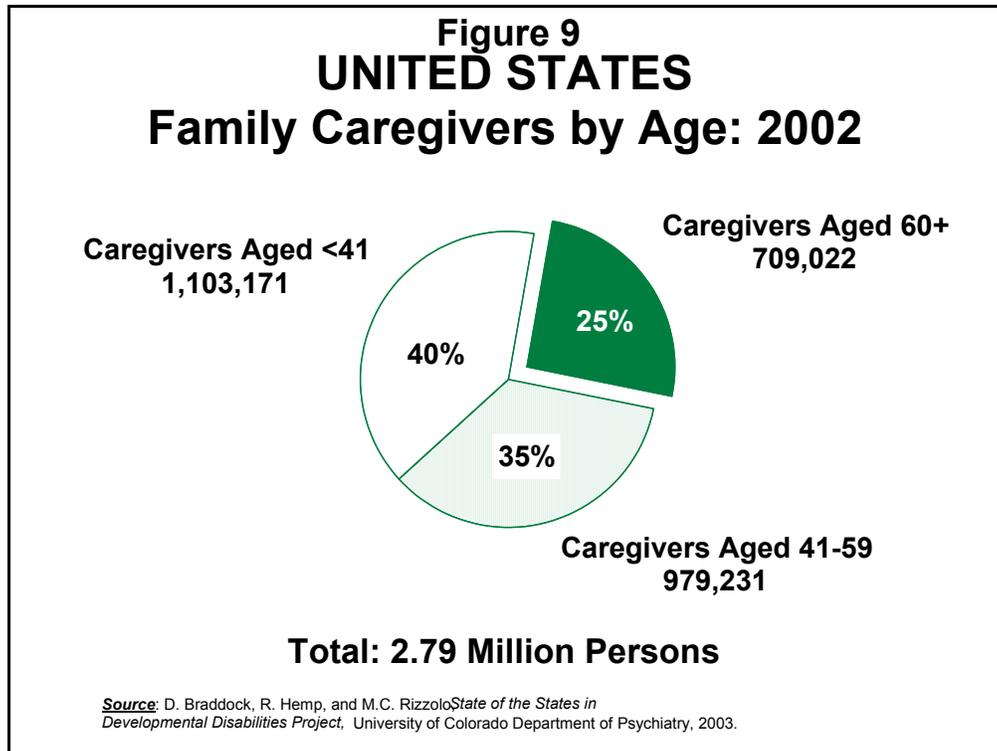
Since 1995, the combined census of public and private institutions for 16 or more persons declined by 5,483 persons per year (4% average annual decline). If the rate of reduction over the next decade continues at this pace, community services and supports would be required for approximately 5,500 individuals per year as they moved from public and private institutions to more individualized settings in the community.

Aging Caregivers. The number of aged persons in our society will double, from 35 million in 2000 to 70 million in 2030 (U.S. Census Bureau, 2002). In 2002, there were an estimated 4.56 million individuals with mental retardation and developmental disabilities in the U.S., using a 1.58% prevalence rate (Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2001). An estimated 61% of these children and adults with MR/DD, 2.79 million, resided with family caregivers (Braddock, 1999, 2002; State of the States, 2003) (*Figure 8*).



Not only are families caring for a substantial portion of all children and adults with MR/DD—fully 25% of caregivers are aged 60 years or more (*Figure 9*). These 709,022 individuals with MR/DD living in aging caregiver families exceed the 451,931 individuals with MR/DD who in 2002 resided in all types and sizes of supervised residential settings. In the relatively near future, it can be anticipated that large numbers of aging family caregivers will be unable to continue to care for their family members with disabilities. Their relatives with developmental disabilities will require out-of-home placements.

In addition to the growing number of baby boom caregivers who will soon be 60 years of age or older, individuals with developmental disabilities are living longer. The impact of increased longevity places additional demands on the residential care system due to the placement duration. Since the 1970s, the average longevity of persons with MR/DD



has increased from 59.2 years to 66.2 years (Janicki, 1996; Janicki, Dalton, Henderson, & Davidson, 1999).

Future Demand for Services. The confluence of trends noted above strongly suggests that, in future years, substantial and steadily increasing numbers of individuals with developmental disabilities will require additional Medicaid assistance for long-term care. The total number of individuals with MR/DD requiring Medicaid long-term care services on an annual basis is approximately 41,000 (see *Note 1*). This figure is roughly 9% of the total number of persons with MR/DD currently living in supervised residential placement in the nation (*Figure 8*). Moreover, during 1990-2002 the total actual out-of-home residential placements for persons with MR/DD in the U.S. increased by an average of only 10,665 per year. This is roughly 25% of the anticipated annual demand.

QUESTION 7. WHAT IMPACT HAS THE ECONOMIC DOWNTURN IN STATE ECONOMIES HAD ON THE MEDICAID PROGRAM AND ON MR/DD SERVICES?

Raymond Scheppach, executive director of the National Governors Association, has called the states' current economic condition "the worst budget crisis states have faced since World War II" (Brownstein, 2002). States are currently facing deficits totaling \$53.5 billion for fiscal year 2004, representing 9.6% of the aggregate of states' general fund budgets (National Conference of State Legislatures, 2003). The fiscal shortfalls exceed 20% of state general fund budgets in Alaska, Arizona, California, and New York; are over 10% of budgets in nine other states; and in 15 states projected deficits constitute 3% or more of the states' 2004 general fund budgets (data were not available for AL, NV and TN).

Despite the severity of the states' economic conditions, there has been little evidence to date that state legislators and governors are balancing their budgets strictly at the expense of Medicaid enrollment or payment levels for persons with disabilities (Holahan, Wiener, Bovbjerg, Ormand, & Zuckerman, 2003). In the early 1990s, the states increased DSH federal revenues and raised taxes to cope with budget problems. But shortfalls today are substantially larger than in the early 1990s, anti-tax sentiment is stronger, and many of the strategies recently employed (e.g., tobacco settlement funds, rainy day funds, state employee salary freezes, workforce reductions, and prison de-population) are diminishing as fiscal options for states. Medicaid's large share of each state's budget assures that the program will remain a potential target as long as there is a continued downturn in states' economies (Smith, Gifford, Ramesh, and Wachino, 2003).

The states are projecting Medicaid cost controls that include a variety of prescription drug cost cuts (e.g. lower payments, use of preferred drug lists, more instances of required prior authorization); provider rate freezes; eligibility restrictions; and benefit reductions such as cutting dental services for adults. Adult Medicaid beneficiaries in the states may expect higher co-payments for drugs or eyeglasses, and for the services of chiropractors or podiatrists (Smith et al., 2003).

The principal Medicaid enrollment reductions to date have been eligibility restrictions affecting from one-half to one million Medicaid beneficiaries, most of whom are parents and children in low-income working families (Ku, Nathanson, Park, Cox, and Broaddus, 2003). However, balancing a state's budget during an economic downturn by reducing Medicaid spending and spending for other goods and services is likely to be counterproductive (Orszag and Stiglitz, 2001). Recent analyses of state Medicaid programs suggest that state economies benefit from maintaining their level of federal Medicaid reimbursement (Division of Research, 2002; Doeksen and St. Clair, 2002; Kilpatrick, Olnick, Luger, and Koo, 2002).

In response to the first signs of economic downturn and increasing unemployment, Medicaid and SCHIP enrollment rose during 2001 and early 2002, providing many low-income families with Medicaid health care to replace lost private insurance (Ku et al., 2003). Without this Medicaid and SCHIP enrollment expansion, there would have been two million more uninsured children and one million more uninsured working-age adults in the first quarter of 2002 (Ku, 2002).

Impact on Developmental Disabilities Programs. Preliminary analysis of the State of the States data for 2002 (State of the States, 2003) indicates that annual, inflation-

adjusted spending growth from 2000 to 2002 was from 1% to 4% in one third of the states and from 5% to 19% the other two thirds of the states. However, as noted, the first signs of what has become a significant series of budget shortfalls in virtually all of the states began in the first quarter of calendar 2001 (National Conference of State Legislatures, 2002).

We reviewed the fiscal year 2003/04 (or biennial 2003/05) budgets for each state and the District of Columbia in order to determine which states' governors were compelled by state budget problems to propose cuts in MR/DD spending in 2004. It appears in this brief examination that many states would need to plan for slow or slightly negative spending growth in 2004 in real economic terms. However, in the nine states discussed below, there was a 4% or larger proposed reduction in community or institutional services spending for persons with MR/DD compared to the 2003 appropriation, or to actual spending in fiscal year 2002. In each case, the budget documents for 2004 were gubernatorial recommendations. The 2004 budget data presented here, therefore, are subject to change during the legislative appropriation process.

Alabama

- The State's fiscal year 2004 governor's budget recommends an 18.85% reduction in virtually every legislative, judicial, and executive agency--for the Department of Mental Health and Mental Retardation (DMH/MR) this would be an inflation-adjusted \$22.4 million reduction from the 2002 appropriation of \$96.5 million (State of Alabama, 2002, 2003). Governor Bob Riley approved Commissioner Kathy Sawyer's recommendation that the DMH/MR save the state \$40 million by closing the Wallace, Brewer-Bayside, and Tarwater Developmental Centers (Beyerle, 2003).

Illinois

- Governor Rod Blagojevich's fiscal year 2004 budget recommended that developmental disabilities community spending be reduced \$16.8 million from the \$952.9 million appropriated in 2003 (an inflation-adjusted 4% reduction from the \$931.5 million expended in 2002) (State of Illinois, 2003). This proposed community spending reduction was noteworthy because of the proposed \$10 million to reopen a closed state institution in Lincoln, and the fact that community MR/DD organizations have not had a cost-of-living increase since 2000 (The Arc of Illinois, 2003).

Kansas

- Governor Kathleen Sebelius' proposed community developmental disabilities spending for 2004 represented a 5% inflation-adjusted decline from the peak of \$246.2 million expended in 2002 (State of Kansas, 2003). The Kansas House Appropriations Committee (2003) endorsed the creation of a commission to study the closure of one or more of the state's three mental health and two developmental disabilities hospitals.

Louisiana

- Louisiana's Executive Budget for FY 2003-2004 proposed the 2004 closing of four of the state's six developmental centers. This would represent a 41% spending reduction from the \$190.6 million expended for the six centers in 2003. The Metropolitan, Northwest, Ruston, and Southwest Developmental Centers would close, leaving the Hammond and Pinecrest Centers (State of Louisiana, 2003).

New Mexico

- Governor Bill Richardson proposed a 7% inflation-adjusted reduction in MR/DD community spending in 2004, compared to the \$135 million expended in 2002 (State of New Mexico, 2003).

Ohio

- On February 5, 2003, the Ohio Department of Mental Retardation and Developmental Disabilities announced the closure of the Apple Creek and Springfield Developmental Centers. Department Director Kenneth W. Ritchey said "We don't have the money in our budget to keep the centers running" (Ohio DMR/DD, 2003; State of Ohio, 2003).

Texas

- In a January 23, 2003, letter to all Texas agencies, boards, universities, and legislators, Governor Rick Perry, Lieutenant Governor David Dewhurst, and Speaker of the House Tom Craddick requested that "you immediately reduce FY 03 spending by an amount equal to at least 7% of your FY 03 general revenue appropriation for all programs except the Foundation School Program, acute care Medicaid, CHIP [Texas' SCHIP Medicaid program] and debt service for previously issued debt."

Utah

- Governor Michael Leavitt recommended a 5% reduction from 2003 to 2004 in the general fund expenditure for Services for People with Disabilities, down from \$44.6 million in 2003. The spending reduction was to be accomplished by reducing staff and funding for services that were not Medicaid-reimbursed.

Wisconsin

- Governor Jim Doyle recommended a \$15 million reduction in 2004 and a \$30 million reduction in 2005 in spending for Northern Wisconsin Center. Wisconsin's institutional spending in 2005 for the three Centers combined was recommended to decline by 2%, down from \$290.7 million in 2004 (State of Wisconsin, 2003).

In the nine states that we identified as proposing rather substantial declines in MR/DD spending in fiscal year 2004, five (Alabama, Kansas, Louisiana, Ohio, and Wisconsin) were planning to close or substantially downsize one or more of their remaining state institutions. Illinois and Utah recommended decreased community spending and New Mexico, that no longer operates a state institution, also would have to accomplish the proposed reduction through reduced community services spending. In Texas, a 7% spending reduction between 2003 and 2004 was requested of virtually all agencies including the Texas Department of Mental Health and Mental Retardation; it is not known what actions the Department would have to take to accomplish the 7% spending reduction.

California and New York were two of the four states in which fiscal year 2004 budget shortfalls constituted 20% or more of their general fund budgets--21% in California and 24% in New York (National Conference of State Legislatures, 2003; State of California, 2003; State of New York, 2003). Governor Davis proposed to address California's \$17.5 billion general fund shortfall through service cuts, savings, state-local program realignment, fund shifts and borrowing (State of California, 2003). Governor Pataki's steps to address New York's \$9.3 billion shortfall included reducing discretionary agency spending, workforce reductions through a hiring freeze and increased early retirement, using favorable interest rates to lower debt costs, increasing federal reimbursement and Medicaid cost-saving measures, and other revenue enhancements.

Remarkably, there were no proposed spending reductions for MR/DD programs over-all in California and New York. Between 2003 and 2004, total recommended spending was to increase 10% for the California Department of Developmental Services

(DDS) and 5% for the New York Office of Mental Retardation/Developmental Disabilities (OMR/DD). The California DDS proposed to offset \$204.7 million in increased caseload cost with savings of \$100 million from the implementation of revised Regional Center purchase of service standards, \$65.7 million from increased federal Title XX/SSBG funds in lieu of general funds, and \$31.6 million from requiring parents, on a sliding scale based on income, to pay a share of the cost of their children's services at Regional Centers. The California Legislative Analyst's Office (2003) also recommended closing two of the Department's five developmental centers in order to reduce spending in future fiscal years. New York's OMR/DD proposed saving \$28.4 million through state and local administrative efficiencies and \$28.1 (annualized) from closing the Institute for Basic Research in Developmental Disabilities. The OMR/DD proposed to continue expansion of the "New York State-CARES" waiting list program initiated in 1998 (State of New York, 2003).

It should be underscored that this discussion of California, New York, and the nine states that proposed spending reductions is based on Gubernatorial recommendations. As this paper is being written, there is ongoing legislative review that may extend into the coming fiscal year. Lack of additional federal Medicaid aid to the states and general economic recovery problems could further compound states' budget difficulties in fiscal year 2004, resulting in additional spending reductions for MR/DD programs in the states discussed and others as well.

PART III: IMPACT OF THE PROPOSED MEDICAID STATE HEALTH CARE PARTNERSHIP ALLOTMENTS PLAN ON RESIDENTIAL CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

QUESTION 8: WHAT IS THE MEDICAID STATE HEALTH CARE PARTNERSHIP ALLOTMENTS PLAN?

The Administration's Medicaid reform plan, "State Health Care Partnership Allotments," was first published in the 2004 U.S. Budget (U.S. Government Printing Office, 2003). Presented both as "extra immediate funding" for the states and "SCHIP-type flexibility," the plan would provide the states an estimated \$3.25 billion in extra federal Medicaid funding in FY 2004, and \$12.7 billion in extra federal funding over seven years (\$1.8 billion per year). There would be "annual allotments" to states for Medicaid and SCHIP, one for "acute care" and one for "long-term care."

The plan would preserve comprehensive benefits for "mandatory" groups, "while giving states expanded flexibility to tailor coverage for 'non-mandatory' recipients and services." As discussed in this paper, funding for optional services constitutes the majority of Medicaid resources for persons with MR/DD. Medicaid services in the states would be built on the SCHIP model: "under SCHIP's flexible benefits, more low-income children and families were provided health care coverage than would have been possible using traditional Medicaid rules." Furthermore, "states would be allowed to transfer some amount (for example, up to 10 percent) between the Acute and LTC allotments" (U.S. Department of Health & Human Services, 2003).

Additional details of the plan offered in Department of Health and Human Services Secretary Thompson's (2003) press conference were as follows:

Under the plan being developed, states would draw from two annual allotments: an acute care health insurance allotment and a long-term care and community services allotment. Amounts would be based on their own level of spending in

2002 in Medicaid and SCHIP, and would be increased each year based on a formula...transferring funds between the two allotments to meet the health care needs of their low-income populations, as well as gaining more flexibility in spending set-aside dollars to cover more people. States that do not choose the new reform option would continue to administer their Medicaid and SCHIP programs under existing rules. All states would also continue to have separate access to unspent SCHIP funding that is still available to them.

The 2004 U.S. Budget (U.S. Government Printing Office, 2003) indicates that spending projections for both the State Health Care Partnership Allotments and for other Medicaid/SCHIP proposals depend on the number of states that choose to participate in the Allotments option. "State allotments would be based on 2002 spending, inflated annually by a specified trend rate. States would be required to meet a Maintenance of Effort for spending on Medicaid and SCHIP services, which would increase each year, but at a lower rate than federal growth" (p. 126).

The Administration's Medicaid proposal has four demonstration projects to promote home and community-based care for individuals with disabilities and two projects providing respite care for caregivers of disabled children and adults. A third demonstration project will test the therapeutic benefits and cost-effectiveness of home and community alternatives to residential care for Medicaid children with psychiatric disabilities, and a fourth will test methods to alleviate shortages of direct care workers in the community.

In addition, the "ticket-to-work spousal exemption" maintains Medicaid coverage for the spouses of individuals with disabilities who are returning to work, there is "presumptive eligibility for home and community-based care services," \$40 million in Real Choice Systems Change Grants to assist states in developing systems of community support, and a "Money Follows the Individual" Rebalancing Demonstration that proposes a five-year demonstration of Medicaid financing for individuals who transition from

institutions to the community (U.S. Government Printing Office, 2003, p. 128). Spending would be \$350 million in FY 2004, and \$1.75 billion over 5 years, helping seniors and people with disabilities participate in community life (Thompson, 2003).

QUESTION 9: IF ENACTED, HOW WILL THE STATE HEALTH CARE PARTNERSHIP ALLOTMENTS PLAN AFFECT THE PROVISION OF SERVICES TO PEOPLE WITH DEVELOPMENTAL DISABILITIES?

The states have raised concern about the adequacy of the \$3.25 billion in extra federal Medicaid funding in 2004 offered in the Administration's proposal. For example, the National Governors Association's press release (2/20/03) called for President Bush to include \$20 to \$40 billion in additional Medicaid funds for states in his \$695 billion economic stimulus proposal. According to the NGA (2003) the impact of state budget shortfalls, the rapid decline of state funds, and the pressure of Medicaid and other health care costs require an immediate program of financial aid to the states. The Association has called for a variety of Medicaid changes, including applying SCHIP's enhanced Federal Medical Assistance Percentage (FMAP) rate to all children's Medicaid services, increasing the FMAP to 90% for Medicaid payments for "dual eligibles" enrolled in both Medicaid and Medicare (Smith, 2001), and enhanced Federal support to the states for the rapidly escalating Medicaid cost of prescription drugs (Cubanski and Kline, 2003).

The 2004 U.S. budget indicates that states would receive \$153 million less in federal Medicaid funding in 2011 than projected under current law, \$4.4 billion less in 2012, and \$8.3 billion less in 2013 (U.S. Government Printing Office, 2003). These are exactly the years that the first baby boomers, born from 1946 to 1964, begin turning 65, an economic and demographic pressure point recently underscored by Greenspan (2003).

There is no information from Administration documents regarding whether or not federal Medicaid funding would continue to decline after 2013 (Nathanson and Lav, 2003).

The economic and demographic problems that now converge around the Medicaid program are in many ways more critical problems than those that confronted the disability field in 1995 when the 104th Congress proposed a similar plan as part of its “Contract with America” (Braddock & Hemp, 1996). In 1995 Medicaid and Medicare together constituted 17% of the federal budget, but Congress proposed reduced spending for the two programs to account for 45% of the federal budget deficit reduction that was scheduled through 2002. Medicaid was re-titled “MediGrant” in the House proposal--the “Seven-Year Balanced Budget Reconciliation Act” (H.R. 2491). MediGrant (and the similar Senate bill) would have restricted unadjusted Medicaid spending growth to between 2% and 6% annually in each state, or roughly one-half the projected Medicaid spending growth under “current law” provisions in effect at that time (Congressional Budget Office, 1995).

Holahan and Liska (1995) developed a Medicaid forecasting model that analyzed general disability beneficiary and expenditure growth from 1993 to 2002 under Congress’ Medicaid reduction assumptions. Based on that model, Braddock and Hemp (1996) estimated that from 25,000 to 84,000 developmental disabilities long-term care beneficiaries would lose Medicaid services if MediGrant or the Senate bill became law--from 10% to 32% of all persons with DD receiving Medicaid long-term care services at that time. Both Houses of Congress passed the MediGrant plan in “The Balanced Budget Act of 1995.” President Clinton vetoed the Act on December 7, 1995. As noted in the discussion above, after double-digit Medicaid spending growth during 1990-95, growth

declined to 3.7 percent per year during 1995-98—primarily attributable to declining DSH payments, TANF welfare reform, and the strong economy (Schneider et al., 2002).

Major components in the Bush Administration's current proposal are reminiscent of the unsuccessful "MediGrant" spending reduction plan: a) "mandatory" Medicaid services would continue, but "non-mandatory" services (e.g., ICF/MR, the HCBS Waiver) would be at the discretion of the states within a dwindling resource base; b) future spending would be tied to a formula that is as yet unspecified; and c) a substantial portion of Medicaid/SCHIP would function much like a block grant to the states (Nathanson and Lav, 2003).

Now a block grant, Social Services (Title XX) funding in 1977 constituted 20% or more of community developmental disabilities spending in 27 states and was a key component in the development of community services in Indiana, Iowa, Nebraska, New Hampshire, New Mexico, South Dakota, and Vermont. Title XX spending peaked at \$255 million in 1980 but declined rapidly after the 1981 enactment of the Social Services Block Grant (PL 97-35). Social Services Block Grant funding for community DD programs, adjusted for inflation, dropped 41% from 1981-2002 (Braddock et al., 2003; Braddock and Hemp, 1996).

Basing the Medicaid State Health Care Partnership Allotments on each state's 2002 spending would differentially benefit states with more comprehensive programs compared to states that, because of economic or political constraints, had deferred expanded Medicaid coverage. Other problems that are inherent in all fixed allotments include: a) no accounting for differing rates of growth in health care costs in individual states; b) no accounting for larger aging populations in some states (which vary between 8.5% in Utah to 17.6% in Florida); c) no capacity to respond to a regional economic downturn, or to localized natural

disasters, epidemics or other unforeseen events that drive Medicaid enrollment and cost; and d) no accounting for those who have lagged in Medicaid expansion, but would now elect to do so with sufficient resources.

Limited funding in the future could force states to make Solomon-like choices between increased numbers of “non-mandatory” elderly and disabled long-term care beneficiaries in the baby boom generation, and the health care needs of children in low-income working families (Nathanson and Lav, 2003). Included under the “non-mandatory” rubric of the new Administration plan are the six important “optional” Medicaid services outlined above, including the ICF/MR program and the HCBS Waiver.

The Consortium for Citizens with Disabilities, a Washington-based coalition of over 100 national disability organizations, is strongly opposed to the Administration’s proposed Medicaid reform plan (CCD, 2003). The CCD’s position statement stresses that there would be life-altering implications to limiting access to health care and long-term care to people for whom Medicaid is a safety net. Noting that the plan is the “wrong solution for the wrong problem,” the CCD is concerned that states would have unchecked flexibility at the expense of beneficiaries and providers.

The Administration’s proposal undermines well-reasoned and time-tested beneficiary protections as though they were responsible for current challenges in financing Medicaid. They are not. Federal oversight of state programs is often the only way to ensure fairness and non-discrimination (p. 2).

In a May 1, 2003, letter to the *New York Times* noted health economist and Albert Einstein College of Medicine professor of pediatrics, Arnold Birenbaum, wrote that the federal-state Medicaid insurance program, with its optional services and waiver flexibility

... goes well beyond being strictly a safety net for the very poor. It keeps people out of nursing facilities and allows children to remain with their families and go to school. Without increased federal aid for Medicaid, the

states' budget woes will certainly lead to further deterioration of our health care system as these creative solutions are inadequately financed or abandoned.

QUESTION 10:
SUMMARY AND CONCLUSION: REFORMING MEDICAID

The Medicaid program, enacted in 1965, is a federal-state partnership that in 2003 is serving nearly 51 million beneficiaries. Medicaid beneficiaries include low-income families with infants and small children in need of the health care and developmental services that Medicaid provides. Nearly half of these children live in families with at least one working parent. Medicaid beneficiaries also include the elderly, and people with disabilities including developmental disabilities. Medicaid provides essential financial support for long-term care services for the elderly and for people with disabilities in nursing facilities and ICFs/MR, and through a range of community-based services including the HCBS Waiver and other “optional” Medicaid services.

Since 1965, Medicaid has been amended frequently (Boben, 2000). There have been state efforts to use Medicaid managed care to control costs. Medicaid coverage was extended to pregnant women and to children in higher income families, and to workers who lose their private insurance. Recent Congressional Medicaid legislation has curtailed disproportionate share hospital (DSH) payments to states, implemented the TANF welfare reform, repealed the Boren Amendment, and enacted the State Children's Health Insurance Program. Medicaid's principal long-term care reform was the 1981 legislation that in part addressed Medicaid's institutional bias with the “cost-neutral” HCBS Waiver. In order to best consider the Bush Administration's Medicaid reform proposal, the Health Care

Partnership Allotments Plan, it is worthwhile to review the three major categories of amendments to Medicaid.

Expansion of Eligibility. Medicaid's EPSDT program in 1967 was designed to improve the developmental period of life for infants and young children with disabilities. In the 1990s, a series of eligibility expansions culminated in the authorization, in 1997, of Title XXI of the Social Security Act, the State Children's Health Insurance Program. Prevention was the principal focus in virtually every instance of Medicaid eligibility expansion. Meeting the early developmental needs of infants and young children pays dividends in terms of improved functioning of youth and adults with disabilities. Providing health care insurance to cover regular medical check-ups for low income working parents and their children can reduce the expense of hospital admissions or other acute medical care and improve quality of life. Dentistry and other specialty Medicaid services are preventive as well.

There were significant Medicaid coverage increases in the 1980s and early 1990s. Nevertheless, the number of Americans lacking health insurance at some point of the year has grown to 57-59 million (Congressional Budget Office, 2003), nearly one quarter of all non-elderly Americans and more than the number of Medicaid beneficiaries. During economic downturns, Medicaid can be an important safety net for families whose working parents lose private health insurance, but Medicaid cannot, alone, address the health care needs of the nearly 60 million uninsured Americans.

Structural Changes in Financing Medicaid. Legislation has amended the financial structure of the Medicaid program. The Balanced Budget Act of 1997 (PL 105-33) curtailed funding for Disproportionate Share Hospital (DSH) and repealed the Boren

amendment, impacting, respectively, the funding available to hospitals and long-term care facilities. Medicaid Disproportionate Share Hospital (DSH) funds were first provided in 1981 (PL 97-35) to inner city teaching and other hospitals at financial risk because they were serving a higher proportion of low-income Medicaid beneficiaries and because of the impact of rising health care costs. As noted, DSH spending was the major cause of increased Medicaid spending in 1990-92.

In the other important structural change, states in 1997 were allowed to require most Medicaid beneficiaries to enroll in managed care organizations without the states obtaining Waivers (PL 105-33). In 2002, 58% of Medicaid beneficiaries were enrolled in managed care. Nevertheless, one of the factors today in rising Medicaid expenditures is that the savings from Medicaid managed care is less than anticipated (Ku and Broaddus, 2003).

Long-Term Care Reform. The HCBS Waiver was designed to be “cost-neutral.” That is, a state must prove to the HHS Secretary that Waiver expansion would be no more expensive than the level of existing ICF/MR or nursing facility spending. The Waiver, along with the optional Medicaid programs of personal care, targeted case management, rehabilitative services and clinic services, have been used in the states to greatly expand community-based long-term care services. Yet the reform of the “institutional bias” of Medicaid is incomplete and further reforms are definitely needed. Only 56% of Medicaid long-term care resources for persons with developmental disabilities are now dedicated to community services. The community Medicaid proportions are only 30% for persons with physical disabilities, and 40% for persons with mental illness (State of the States, 2003).

The fundamentally institutional orientation of the Medicaid program remains in need of reform.

The Administration's Health Care Partnership Allotments Plan. One important feature of the Administration's plan is offering states flexibility in order to reduce their escalating long-term care costs. The Medicaid section of the Administration's FY 2004 budget points to the dramatic contrast in funding provided to various Medicaid beneficiary groups: "The elderly and disabled are one-third of Medicaid beneficiaries, but account for two-thirds of its spending" (U.S. Government Printing Office, 2003, p. 125).

Long-term care spending accounts for nearly half of Medicaid spending for the aged and disabled, and these long-term care costs per aged/disabled Medicaid beneficiary are driven in large part by the cost of public and private institutional care. For example, from 1992 to 2000 the nationwide, inflation-adjusted Medicaid long-term care cost per beneficiary with a developmental disability declined 15%. However, the ICF/MR component of that DD cost per beneficiary increased 72%. In other words, use of the HCBS Waiver moderated ICF/MR costs that were escalating due to a combination of factors (i.e., the downsizing of facilities and the consequent increased cost per beneficiary, and the continued expense of physical plant and staffing improvements to meet HCFA/CMS certification standards).

Continued Medicaid reform is certainly needed. Four conditions are critical in weighing the potential advantages and disadvantages of the Administration's reform proposal. First, it is important that disability advocates, service providers, and government policymakers learn from the positive experiences of those states that have successfully supplanted ICFs/MR with HCBS Waiver services (see *Table 2*) and that have implemented

“cash and counseling” demonstrations. In six states--Alaska, Arizona, Colorado, New Hampshire, Oregon, and Vermont-- Waiver participants constitute more than 90% of all Medicaid long-term care beneficiaries with MR/DD, and the Waiver proportion is 80-90% in another 12 states.

Arkansas, Florida, Iowa, New Jersey, and New York are using “cash and counseling demonstrations” that put Medicaid money directly into the hands of consumers. New Hampshire and South Carolina have developed similar programs called “independence plus” Waivers (Brown & Foster, 2000; Centers for Medicare and Medicaid Services, 2003; Foster, Brown, Phillips, Schore, and Carlson, 2003). The 18 states that were leaders for years in use of the MR/DD Waiver and in addition the seven states that now have initiated consumer-directed Medicaid programs have compiled experiential histories that can benefit other states. These state innovators can provide information about the collaboration of stakeholders including parents of institutionalized children, professionals, private provider organizations, and individuals with disabilities. These states have experience with the resources and strategies needed to develop an infrastructure of community services housing, work, recreation and other individualized services.

A second critical condition in ongoing Medicaid reform is the need to improve the quality of Medicaid community services. As noted, nationwide direct support staff wages are substantially below the wages of institutional staff, and are only about half (55%) the average wage of all workers that are covered by unemployment insurance. The Administration plan proposes a demonstration project to alleviate workforce shortages. In addition, Medicaid funding must be available to recruit and retain qualified staff who can maintain a constant and supportive role in the lives of individuals with developmental

disabilities in community long-term care arrangements. Medicaid funding is also needed for applied technologies that increase independence without compromising individuals' safety, and that can serve as an important complement to staff in Medicaid long-term care settings.

The third critical condition in ongoing Medicaid reform pertains to the transition from institutional to community services. A state in such transition--and most states are still in transition to some degree--must finance adequate services in downsized institutions while simultaneously developing community residential and related support services. Simultaneous Medicaid funding for both downsizing ICFs/MR and expanding HCBS Waiver services, giving rise to escalating Medicaid long-term care costs during 1977-89 (*Figure 6*), was an essential developmental stage for the states that have now achieved long-term care reform. Successful community integration cannot be achieved across all states, however, if the long-term care Medicaid funding base is at risk after the year 2010, as is proposed in the Administration's Plan. This is the case even if the Plan permits greater flexibilities in program funding at the state and local levels.

Finally, effective Medicaid reform requires continuing the legislative and regulatory innovations that were forged from the dynamic federal-state Medicaid partnership of the past two decades. In the 1980s, states were slow to implement HCBS Waiver services due in large part to a number of federal restrictions. In the 1990s, Congressional legislation addressed many of these procedural and programmatic restrictions. All states, those with strong Waiver programs and those without, benefited from legislation and federal regulations that authorized longer Waiver approval periods and that simplified states'

Waiver applications. More flexible interpretations of “cost neutrality” meant that states that closed their ICFs/MR could expand Waiver services to address unmet need.

Furthermore, the Health Care Financing Administration (HCFA) and now the Centers for Medicare and Medicaid Services (CMS) actively promoted system change and the development of community services in the states. Technical assistance and federal funding were afforded the states in conjunction with the *Olmstead* Supreme Court decision (*Olmstead v. L.C.*, 1999), and recently, with the President’s New Freedom Initiative.

When individuals with mental and physical disabilities move to the community with adequate supports, many societal benefits accrue--including increased consumer satisfaction and community integration that often lead to gainful employment and the use of less costly generic support services. One promising component in the Bush Administration proposal is its recognition of the need for community-based service alternatives to nursing homes for the elderly and for people with disabilities. Persons with mental illness and physical disabilities lag substantially behind persons with developmental disabilities in access to the HCBS Waiver and other community Medicaid services in the states. Long-term care for persons with mental retardation/developmental disabilities has become more fully manifest as a civil rights issue than it has for persons with physical disabilities and mental illness (Braddock, 2002a). The Administration’s plan recognizes the ultimate goal of a flexible Medicaid program that can afford community-based services to all persons with disabilities. Just as important, however, is an adequate level of ongoing Medicaid financial support to the states as they develop the range of community options that are needed.

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Note 1: Estimating annual demand for services: Of 70,000 students with mental retardation, multiple disabilities, and autism exiting special education, an estimated 10% (7,000) may require supervised residential services (see supervised residential proportion of all persons with MR/DD--**Figure 8**); 5,500 individuals were estimated to move from public and private institutions to community long-term care settings each year based on the 1995-02 average annual decline; and 5% of individuals with MR/DD residing with aging caregivers, 34,000 persons, were estimated to be in need of supervised residential services each year. This totals 46,500 individuals of whom 41,000 individuals exiting special education and living with aging caregivers are not yet Medicaid long-term care beneficiaries.