

## **BRIEFING PAPER**

## Repeal of the Institution for Mental Diseases Exclusion

#### Background

Schizophrenia and manic-depressive disorder (hereinafter "severe brain disorders") are physical diseases of the brain. They are no more a "choice" for the individuals who suffer from them than are other physical brain disorders such as epilepsy, Alzheimer's disease and multiple sclerosis. Research has shown significant differences between brains with schizophrenia and manic-depressive disorder, and unaffected brains. Those differences have been verified in studies of affected and not-affected identical twins, and studies of those who have received anti-psychotic medication and those who did not.

About 40 percent, or 1.4 million of the 3.5 million Americans who suffer from severe brain disorders are not receiving treatment at any given time. A major reason why so many are not being treated is that, because of the effects of the illness on their brain, they lack awareness of their illness. Studies have shown that approximately half of all patients suffering from schizophrenia and mania have markedly impaired awareness of their illness as measured by tests of insight; thus, they are similar to some patients with cerebrovascular accidents (strokes) and with Alzheimer's disease. Such individuals typically refuse to take medication because they do not believe they are sick.

Persons with severe brain disorders constitute between 150,000 and 200,000 of the estimated 600,000 homeless persons in the United States. It is estimated that as many as 283,800 are in jail or prison, primarily charged with misdemeanors, although it was found that the crimes committed by some of the prisoners charged with felonies were largely caused by their psychotic thinking. As a result, the Los Angeles County Jail, with some 3,400 mentally ill prisoners, has become the largest psychiatric "treatment facility" in the country. New York's Rikers Island Jail is the second largest with some 2,800 mentally ill prisoners. 10

Ten to 13 percent of individuals with schizophrenia 11 and 15 to 17 percent of those with

manic-depressive disorder<sup>12</sup> will die from suicide. The rate for the general population is about one percent. <sup>13</sup> While they constitute only about 0.5 percent of the general population, persons with untreated severe brain disorders account for 4.3 percent of all homicides. They commit 12.3 percent of spousal murders, 15.9 percent of murders of children by a parent, 25.1 percent of murders of a parent by a child and 17.3 percent of murders of a sibling by a sibling.<sup>14</sup>

Virtually all long-term and much short-term hospitalization for severe brain disorders is in state psychiatric hospitals. <sup>15</sup> In 1955, with a population of only 164 million, the United States had 558,239 patients <sup>16</sup> in state and county psychiatric hospitals. By 1996, with a population that had increased to 265 million, the number of patients in state and county psychiatric hospitals had dropped to only 61,722. <sup>17</sup> This is an effective deinstitutionalization rate of about 93 percent. <sup>18</sup> Since 1996 the number of state psychiatric hospital beds has continued to decrease. For example, in 1996, New York had 8,886 patients in their state psychiatric hospitals. By May of 1999 New York had only 6,000 such beds remaining. <sup>19</sup>

With good community services, the vast majority of persons with severe mental illnesses do not require long-term hospitalization. Nevertheless a small group still requires the long-term care and supervision of a psychiatric hospital or the equivalent, but in some areas continue to face lengthy waiting lists for admission to many of the state psychiatric hospitals.

## Deinstitutionalization and the "Forgotten Population"

Deinstitutionalization is fundamentally a good concept. Many persons with severe brain disorders who are not currently receiving care can be cared for in community settings such as group homes. NAMI (formerly the National Alliance for the Mentally III) is actively promoting the Program of Assertive Community Treatment (PACT) model for treating those individuals who are capable of living within the community, but who require assistance in maintaining their treatment. NAMI also supports the use of outpatient commitment and involuntary commitment as a last resort for those persons who will not otherwise receive proper treatment. The treatment standard promoted by NAMI is that:

States should adopt broader, more flexible standards which would provide for involuntary commitment and/or court ordered treatment when an individual:

- (A) is gravely disabled, which means that the person is substantially unable, except for reasons of indigence, to provide for any of his or her basic needs, such as food, clothing, shelter, health or safety; or
- (B) is likely to substantially deteriorate if not provided with timely treatment; or
- (C) lacks capacity, which means that as a result of the brain disorder the person is unable to fully understand or lacks judgment to make an informed

decision regarding his or her need for treatment, care or supervision. 20

While it is unclear how many state psychiatric hospital beds will be required once (and if) adequate community-based services are in place, deinstitutionalization has, in many states, resulted in too few beds being made available for those who require the long-term structure of a psychiatric hospital or the equivalent.

An estimated 20% of individuals with severe mental illness do not respond to traditional community treatment. This population requires long-term structured residential or institutional care. <sup>21</sup> The population of those with the most severe, disabling and chronic forms of severe mental illness has been labeled "The Forgotten Population" because their needs are often overlooked in the downsizing of state hospitals and in the planning and implementation of community services. <sup>22</sup>

One major factor leading the states to close their psychiatric hospitals is an aspect of Federal Medicaid reimbursement policy known as the IMD Exclusion. (See What is the IMD Exclusion, *infra*.) In a nutshell, this exclusion prevents a state psychiatric hospital from receiving federal Medicaid funds for its patients, whereas patients hospitalized on the psychiatric ward of a general hospital or treated in a community setting are eligible for such funds. Without federal funds, state hospitals close. The result of discharging patients and then closing the state hospital beds is that states save *state* money. If a patient then needs rehospitalization, it is to a general hospital that is not usually properly equipped to handle long-term psychiatric care. And the quality of care is generally poorer than in private or state psychiatric hospitals.<sup>23</sup>

The IMD Exclusion thus became the driving force behind deinstitutionalization as states attempted to save their own funds by closing state hospitals, effectively transferring costs to the Federal Government. The fact that many of the patients should not have been discharged and were not receiving follow-up care got lost in the rhetoric. A study carried out in Baltimore in 1981, for example, found that one-half of all individuals with schizophrenia who were living in the community were receiving no care whatsoever.<sup>24</sup> Yet no changes were made to care for those affected by deinstitutionalization.

#### What is the IMD Exclusion?

As defined by statute, "[t]he term 'institution for mental diseases' means a hospital, nursing facility, or other institution of more than 16 beds, that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases, including medical attention, nursing care, and related services." <sup>25</sup>

Current federal law prohibits Medicaid reimbursement for any person over age 21 and under age 65 who resides in an institution for mental diseases (IMD), even for treatment unrelated to mental illness.<sup>26</sup> This prohibition is commonly referred to as the IMD Rule or IMD Exclusion. State and private psychiatric hospitals are IMDs as are nursing homes that specialize in caring for the severely mentally ill.

#### Origin and History of the IMD Exclusion

State psychiatric hospitals were first created as asylums for the insane -- a humane alternative to the poor houses and jails, characterized by victimization and maltreatment, where the severely mentally ill had previously been abandoned.<sup>27</sup>

In 1848, social activist Dorothea Dix observed that

Humanity requires that every insane person should receive the care appropriate to his condition.... Hardly second to this consideration is the civil and social obligation to consult and secure the public welfare: first in affording protection against the frequently manifested dangerous propensities of the insane; and second, by assuring seasonable and skillful remedial care, procuring their restoration to usefulness as citizens of the republic, and as members of the communities.<sup>28</sup>

Ms. Dix successfully lobbied Congress to finance her asylums for the insane only to have the legislation vetoed in 1854 by President Franklin Pierce on the grounds that

If Congress has power to make provision for the indigent insane . . . it has the same power to provide for the indigent who are not insane.... It has the same power to provide hospitals and other local establishments for the care and cure of every species of human infirmity.... [T]he several states . . . may themselves become humble supplicants for the bounty of the Federal Government, reversing their true relations to this Union.<sup>29</sup>

In other words, President Pierce rejected the creation of a system of federally funded asylums because the public provision of "care and cure" for "human infirmity" was a state responsibility under our federal system of government. As a result, the states were left to build and finance their own hospitals to care for the severely mentally ill. <sup>30</sup>

Despite the failure to obtain federal financing for asylums, the humanitarian effort to house persons with severe mental illness in state-funded asylums rather than incarcerate them in jails was generally successful. In 1880, when the most complete census of mentally ill individuals ever carried out in the United States was conducted, only 0.7 percent of persons incarcerated in jails and prisons were said to be mentally ill 31

In 1963, more than a century after President Pierce rejected a federal role in funding asylums, Congress again addressed the issue of care and treatment of the severely mentally ill. Congress observed that "[t]he average expenditure per patient day in State mental institutions is \$4.50 as compared with \$12 in the Veterans' Administration psychiatric hospitals and about \$32 per day in community general hospitals." It also found that "[t]he evidence seems clear. Either we must develop the quantity and quality of community services . . . or we will have to undertake a massive program to strengthen the State mental hospitals."

Rather than strengthen the state hospitals, Congress opted to fund construction of community mental health centers. These centers were to "include an emergency psychiatric unit, inpatient services, outpatient services, day and night care, foster home care, rehabilitation programs, and general diagnostic and evaluation services." The Kennedy Administration testified before Congress that the Act would reduce the population of the state hospitals by 50 percent within a decade or two.<sup>35</sup>

Two years later, when Congress enacted Medicaid, it again stressed that "it is important that States move ahead promptly to develop comprehensive mental health plans as contemplated in the Community Mental Health Centers Act of 1963." Except for the aged, Medicaid reimbursement was prohibited for persons residing in IMDs. Funding for the aged in IMDs was made "dependent upon a showing of satisfactory progress toward developing and implementing a comprehensive mental health program – including utilization of community mental health centers, nursing homes, and other alternative forms of care."

Justice Lewis F. Powell observed in 1980 that "[t]he residual exclusion of large state institutions for the mentally ill from Federal financial assistance rests on two related principles: States traditionally have assumed the burdens of administering this form of care, and the Federal Government has long distrusted the economic and therapeutic efficiency of large mental institutions." 37

This second point should not be ignored. As recently as 1992, the Health Care Finance Administration (HCFA), which administers Medicaid, reported to Congress that "[i]n the treatment of mental disorders, hospitalization is the most expensive form of care, but no more effective (on average) than alternative, community-based programs." "No findings . . . support a recommendation for any statutory change in the IMD Exclusion."

The Federal government is also concerned about cost and the cost-shifting effect of eliminating the IMD Exclusion. The 1992 HCFA report states that

Conservative estimates suggest that this statutory change would increase total Medicaid expenditures by \$3.10 billion, of which \$1.73 billion would be the Federal cost and \$1.36 billion the state and local cost. However, much of these increased expenditures would simply represent a substitution of Federal funding for State and local funding. State and local governments are estimated to save \$870 million if the IMD Exclusion were to be eliminated.

State and local governments would save money because federally subsidized Medicaid funds would be substituted for non-eligible expenditures.

While prohibited from receiving direct Medicaid reimbursement, IMDs can and do receive Federal DSH payments.

#### What are DSH Payments?

Because of low Medicaid reimbursement rates, private insurance has historically subsidized patient's costs covered by Medicaid. Hospitals with a high proportion of low-income patients simply lost money. Beginning in the early 1980s, Congress took steps to correct this problem by authorizing additional payments to Disproportionate Share Hospitals (DSH).<sup>41</sup>

While there are other requirements, a hospital will generally qualify as a DSH if it has:

- 1. A Medicaid utilization rate more than one standard deviation above the mean Medicaid utilization rate for all hospitals in a state; or
- 2. A low-income utilization rate exceeding 25 percent. 42

Because patients in an IMD are often indigent, states are able to obtain DSH funding for IMDs even though they are otherwise excluded from Medicaid reimbursement.

### A Brief History of DSH Payments

By the early 1990s, the state governments discovered that DSH payments were a great way to generate income. Between 1990 and 1992 DSH payments grew from \$1.4 billion to \$17.5 billion.

Responding to the rapid growth in DSH payments, the Medicaid Voluntary Contribution and Provider-Specific Tax Amendments of 1991 (P.L. 101-234) imposed limitations on DSH payments beginning in 1992: national DSH payments were not to exceed 12 percent of total Medicaid costs. Further limits were added in 1993, and again under the Balanced Budget Act of 1997 (BBA). These include:

- 1. Beginning in fiscal year (FY) 1998, states are barred from spending more of their DSH funding on IMDs than they did in 1995 in both absolute terms and as a percentage of total DSH spending.
- 2. Beginning in FY 2001, DSH funding will be further limited to the following percentages of a state's DSH funding:

FY2001: 50 percent FY2002: 40 percent FY2003 and later: 33 percent

HCFA provides the following example of how DSH payments will be calculated for three states in fiscal year 2003.<sup>43</sup>

	State A	State B	State C
1. Prior Year's Federal DSH Allotment	242,000,000	60,000,000	62,000,000
2. Prior Year's CPI-U	6.0%	6.0%	6.0%
3. Calculated 2003 Federal DSH Allotment	256,520,000	63,600,000	65,720,000
4. Projected Current Year Total Federal Medical	1,500,000,000	1,200,000,000	525,000,000
Assistance Expenditures as Adjusted by HCFA.			
5. Maximum Percentage	12.0%	12.0%	12.0%
6. 12% of Adjusted Federal Medical Assistance	180,000,000	144,000,000	63,000,000
Expenditures (4 X 5)			
7. Actual 2003 Federal DSH Allotment	242,000,000	63,600,000	63,000,000

**State A's** prior year federal DSH allotment of \$242 million represents approximately 16 percent of the state's total federal medical assistance expenditures as estimated for 2003 (\$1.5 billion). Since State A's prior year federal DSH allotment exceeds 12 percent of total federal medical assistance expenditure estimates for 2003, the state's federal DSH allotment for 2003 cannot be increased by the CPI and will remain \$242 million.

**State B's** prior year federal DSH allotment of \$60 million represents approximately five percent of the state's total federal medical assistance expenditures as estimated on the HCFA 37 (\$1.2 billion). Since State B's prior year federal DSH allotment does not exceed 12 percent of total federal medical assistance expenditure estimates for 2003, the state's federal DSH allotment for 2003 will be \$63.6 million, or \$60 million increased by the CPI.

**State C's** prior year federal DSH allotment of \$62 million represents 11.8 percent of the state's total federal medical assistance expenditures as estimated for 2003 on the HCFA 37 (\$525 million). Because \$62 million is less than 12 percent of total federal medical assistance expenditure estimates for 2003, the state's federal DSH allotment for 2003 can be increased by the CPI, but capped at 12 percent of total federal medical assistance expenditures. State C's federal DSH allotment for FY 2003 is \$63 million.

Section 4721(b) of the BBA provides for a limit on the amount of federal financial participation available for IMD DSH payments. Federal financial participation is not available for IMD DSH payments that exceed the lesser of:

- 1. A state's 1995 total computable mental health DSH expenditures applicable to the 1995 DSH allotment as reported as of January 1, 1997; or,
- 2. The amount equal to the product of the State's current year total computable DSH allotment (as calculated above) and the "applicable percentage." 44

For FYs 1998-2000, the "applicable percentage" is defined as the ratio of 1995 total computable share mental health DSH payments (applicable to the 1995 DSH allotment) to the 1995 total computable share total DSH expenditures (applicable to the 1995 DSH allotment). For FYs 2001 and beyond, the applicable percentage is defined as the lesser of the applicable percentage as computed above, or 50 percent for fiscal year 2001; 40 percent for fiscal year 2002; and, 33 percent for each succeeding year.

HCFA will publish annually a state-specific chart in the Federal Register that will contain each state's DSH limitation. See Appendix B.

These planned federal reductions in the total amount of DSH funding and of the percentage of DSH funding for IMDs will result in further financial pressure on the states to close state psychiatric hospitals to save money.

#### IMD Exclusion Waivers to Implement Medicaid Managed Care

A number of states have received waivers of the IMD Exclusion as part of Section 1115 demonstration projects to implement mandatory Medicaid managed care programs. These waivers appear to have the following elements in common:<sup>46</sup>

- 1. assurance of budget neutrality;
- 2. limitation of coverage to acute episodes only; and
- 3. controls to assure that the lengths of stay are minimized.

Thus, even in states with Section 1115 waivers, Medicaid does not cover individuals requiring long-term hospitalization and savings from elsewhere must finance any Medicaid payments received by an IMD in the managed care plan.

#### Implications of Repeal of the IMD Exclusion

The Federal Government, at rates ranging from 50 percent to 80 percent, reimburses states for Medicaid expenditures. <sup>47</sup> By excluding IMDs from Medicaid reimbursement, the states have a significant financial incentive to treat persons with severe brain disorders in other venues, even if those venues may be both more costly and less effective.

For example, in 1992 treatment in a general hospital was estimated to cost approximately \$499.05 per day and in a private psychiatric hospital approximately \$485.67. While the cost of treatment in state psychiatric hospitals varies from state to state, it is estimated to cost approximately \$200 per day less than in a general hospital Per let's say \$300 per day. The cost of incarceration is about \$137 per day.

Using these figures, the daily cost to the states of each alternative is as follows:<sup>51</sup>

	50% reimburs.	65% reimburs.	80% reimburs.	
General Hospital	\$249.53	\$174.68	\$99.81	
Private Psych. Hosp.	485.67	485.67	485.67	
State Psych. Hosp.	300.00	300.00	300.00	
Jail & Prison	137.00	137.00	137.00	

Rev 11/3/99

Without the IMD Exclusion the relative cost to the states changes dramatically:

	50% reimburs.	65% reimburs.	80% reimburs.
General Hospital	\$249.53	\$174.68	\$99.81
Private Psych. Hosp.	242.84	169.98	97.13
State Psych. Hosp.	150.00	105.00	60.00
Jail & Prison	137.00	137.00	137.00

By eliminating the IMD Exclusion, the states will have a strong financial incentive to maintain their state and county psychiatric hospitals when compared to the alternatives. It will actually cost the states more money to close their psychiatric hospitals when the alternative is treatment in other hospitals, and incarcerating the ill becomes at best nominally cheaper than treating them.

#### Effect of Repeal on Community Services

Estimates of the cost of Community-based treatment, in the form of PACT, range from "\$8,000 to \$12,000 a year per client" (\$22 to \$33 per day) to \$29,965 a year per client (\$82 per day). It therefore remains cost-competitive when compared to hospitalization or incarceration. Other forms of assisted community treatment will likewise remain cost-competitive.

Moreover, the recent Supreme Court decision in *Olmstead v. L.C.* makes it clear that under the Americans with Disabilities Act (ADA), states are generally required to provide care in a community based setting provided that the "State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." <sup>54</sup>

Repeal of the IMD Exclusion is therefore not expected to adversely impact efforts to establish community based care for appropriate individuals, but rather to assure appropriate treatment for those individuals who are too ill to participate in such programs and who require care in an IMD.

There is no current cap on Medicaid as there is on DSH payments. As previously cited, a 1992 HCFA study estimated the cost of repeal of the IMD Exclusion at \$3.2 billion dollars. Given the general under-funding of treatment for the mentally ill, large projected federal budget surpluses, expansion of Medicare payments and new proposed social programs, it is time for the mental illness community to argue for increased funding rather than how to divide an ever-decreasing budgetary pie.

Even if repeal is made contingent on federal budget neutrality, this should still mean more money for the treatment of severe mental illness. Medicaid will subsidize the cost of treatment in an IMD to the same extent as the treatment of other illnesses in other venues. This will reduce the total cost to the state for treatment of severe brain

disorders relative to other covered illnesses.

### What Should be Done?

The Institutions for Mental Diseases (IMD) Exclusion should be abolished as part of a broad federal and state re-evaluation of how mental health services are funded. As long as there remains a huge financial incentive for states to discharge patients with severe mental illnesses, but no financial incentive to provide aftercare, America's jails and streets will continue to be the *de facto* asylums for the mentally ill of the 1990s.

NAMI's policy articulates the issue well:

NAMI calls upon the Congress to repeal the IMD rule and to adopt uniform standards of Medicaid eligibility based upon individual resources and the need for physical and mental illness services, rather than upon the location in which services are provided or the residence of the recipient.<sup>55</sup>

Appendix A.

Patients in Public Psychiatric Hospitals, 1955 – 1996

State	Patients In Public Psych. Hospitals 12/31/55	Patients In Public Psych. Hospitals 12/31/94	Patients In Public Psych. Hospitals 1996	Actual Deinstitutionalization Rate in % 1955-96
Alabama	7,197	1,649	1,305	81.9
Alaska			66	n/a
Arizona	1,690	462	372	78.0
Arkansas	5,086	183	140	97.2
California	37,211	3,814	4,425	88.1
Colorado	5,720	775	458	92.0
Connecticut	8,668	958	702	91.9
Delaware	1,393	539	462	66.8
Florida	8,026	2,766	2,628	67.3
Georgia	11,701	3,239	2,868	75.5
Hawaii			167	n/a
Idaho	1,221	138	150	87.7
Illinois	37,883	2,845	1,802	95.2
Indiana	11,151	1,320	2,485	77.7
Iowa	5,336	513	431	91.9
Kansas	4,420	883	928	79.0
Kentucky	7,700	645	591	92.3
Louisiana	8,271	1,091	1,095	86.8
Maine	2,996	440	421	85.9
Maryland	9,273	1,820	1,624	82.5
Massachusetts	23,178	793	705	97.0
Michigan	21,798	3,711	1,513	93.1
Minnesota	11,449	1,593	1,318	88.5
Mississippi	5,295	1,208	2,165	59.1
Missouri	12,021	1,109	1,268	89.5
Montana	1,919	196	210	89.1
Nebraska	4,788	599	576	88.0
Nevada	440	760	382	13.2
New Hampshire	2,733	137	173	93.7
New Jersey	22,262	3,405	3,181	85.7
New Mexico	950	209	170	82.1
New York	96,664	11,286	8,886	90.8
North Carolina	9,960	2,203	1,953	80.4
North Dakota	1,993	213	226	88.7
Ohio	28,663	1,849	1,347	95.3
Oklahoma	8,014	675	526	93.4
Oregon	4,886	855	750	84.7
Pennsylvania	40,920	4,787	3,976	90.3
Rhode Island	3,442	63	102	97.0
South Carolina	6,042	830	974	83.9
South Dakota	1,603	317	274	82.9
Tennessee	7,693	1,142	1,188	84.6
Texas	16,445	2,930	2,225	86.5
Utah	1,337	326	304	77.3
Vermont	1,294	63	60	95.4
Virginia	11,303	2,540	1,095	90.3
Washington	7,631	1,330	1,201	84.3
Washington, D.C.	7,318	1,148	917	87.5
West Virginia	5,619	224	216	96.2
Wisconsin	14,981	891	619	95.9
Wyoming	655	147	102	84.4
Totals	<u>558,239</u>	<u>71,619</u>	<u>61,722</u>	<u>88.9</u>

# Appendix B.

# DSH Allotments Fiscal Years 1998 - 2002

(in millions of dollars)

	-	EV OF MIL	-	-	-	-	-
04-4-	E\/ 0E	FY 95 MH	E)/ 00	E)/ 00	<b>5</b> \/ 00	EV 04	EV 00
State	FY 95	% of DSH	FY 98	FY 99	FY 00	FY 01	FY 02
Alabama	294	1%	293	269	248	246	246
Alaska	9	95%	10	10	10	9	9
Arizona	81	0%	81	81	81	81	81
Arkansas	2	0%	2	2	2	2	2
California	1,458	0%	1,085	1,068	986	931	877
Colorado	191	0%	93	85	79	74	74
Connecticut	225	33%	200	194	164	160	160
Delaware	4	100%	4	4	4	4	4
District of Columbia	25	16%	23	23	23	23	23
Florida	188	45%	207	203	197	188	160
Georgia	255	0%	253	248	241	228	215
Hawaii	1	0%	0	0	0	0	0
Idaho	3	0%	1	1	1	1	1
Illinois	207	16%	203	199	193	182	172
Indiana	251	56%	201	197	191	181	171
Iowa	3	0%	8	8	8	8	8
Kansas	44	87%	51	49	42	36	33
Kentucky	153	0%	137	134	130	123	116
Louisiana	919	9%	880	795	713	658	631
Maine	105	27%	103	99	84	84	84
Maryland	80	75%	72	70	68	64	61
Massachusetts	305	17%	288	282	273	259	244
Michigan	249	70%	249	244	237	224	212
Minnesota	13	0%	33	16	16	16	16
Mississippi	143	0%	143	141	136	129	122
Missouri	436	28%	436	423	379	379	379
Montana	0	0%	0	0	0	0	0
Nebraska	4	27%	5	5	5	5	5
Nevada	37	0%	37	37	37	37	37
New Hampshire	164	31%	140	136	130	130	130
New Jersey	643	29%	600	582	515	515	515
New Mexico	5	0%	5	5	5	5	5
New York	1,458	15%	1,512	1,482	1,436	1,361	1,285
North Carolina	278	69%	278	272	264	250	236
North Dakota	1	82%	1	1	1	1	1
Ohio	382	15%	382	374	363	344	325
Oklahoma	13	14%	16	16	16	16	16
Oregon	17	56%	20	20	20	20	20
Pennsylvania	95	1%	62	60	58	55	52
South Carolina	311	17%	313	303	262	262	262
South Dakota	1	0%	1	1	1	1	1
Tennessee	0	n/a	0	0	0	0	0
Texas	958	19%	979	950	806	765	765
Utah	3	20%	3	3	3	3	3
Vermont	23	26%	18	18	18	18	18
Virginia	73	5%	70	68	66	63	59
Washington	181	51%	174	171	166	157	148
West Virginia	19	21%	64	63	61	58	54
	7	35%	7	7	7	7	
Wyoming							7
Wyoming	0	n/a	0	0	0	0	0

Sources:

Federal Register, October 8, 1998 HCFA, MB, OMM, Division of Financial Management

<sup>1</sup> E. FULLER TORREY, OUT OF THE SHADOWS: CONFRONTING AMERICA'S MENTAL ILLNESS CRISIS, 4-5 (1997).

<sup>4</sup> Regier, D.A., Narrow, W.E., Rae, D.S., Manderscheid, R.W., Locke, B.Z., Goodwin, F.K. *The* de facto US Mental and Addictive Disorders Service System: Epidemiologic Catchment Area prospective 1-vear prevalence rates of disorders and services, 50 ARCHIVES OF GEN. PSYCHIATRY 85-94 (1993).

<sup>5</sup> Amador, X.F., Strauss, D.H., Yale, S.A., and Gorman, J.M. Awareness of Illness in

Schizophrenia.17 SCHIZOPHRENIA BULL. 113–132 (1991).

<sup>6</sup> Ghaemi, S.N. *Insight and Psychiatric Disorders: A Review of the Literature, with a Focus on* its Clinical Relevance for Bipolar Disorder. 27 PSYCHIATRIC ANNALS 782-790 (1997).

The National Institute of Mental health (NIMH) and the National Center for Health Statistics (NCHS) conducted a national survey in 1989, which found that an estimated 200,000 mentally ill persons are homeless on any given day. CONG. RES. SERVICE, MEDICAID SOURCE BOOK: BACKGROUND DATA AND ANALYSIS (1993) (App. E: Medicaid Services For The Mentally III). Some estimates indicate that 20 to 40 percent of the homeless population suffer from a serious mental illness. Id. at 914-915. Other research studies have estimated that approximately onethird of the homeless population suffers from schizophrenia or bipolar disorder and have concluded that at least 150,000 homeless individuals in America suffer from these psychiatric disorders. See testimony of E. Fuller Torrey before the United States Senate, Committee on Finance, on *Deinstitutionalization*, Fed. News Service, (May 10, 1994) and E. Fuller Torrey, SURVIVING SCHIZOPHRENIA at 1-2.

<sup>8</sup> DITTON, PAULA M. MENTAL HEALTH AND TREATMENT OF INMATES AND PROBATIONERS, BUREAU OF JUST. STAT. SPECIAL REP. (1999)

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<sup>10</sup> Fox Butterfield, *Prisons Replace Hospitals for the Nation's Mentally III*, N.Y. TIMES, March 5, 1998. at A1

<sup>11</sup> C.B. Caldwell, I.I. Gottesman, Schizophrenics Kill Themselves Too: A review of Risk Factors for Suicide, 16 Schizophrenia Bulletin 571-89 (1990)

<sup>12</sup> F.K. GOODWIN, K.R. JAMISON, MANIC-DEPRESSIVE ILLNESS 230 (1990)

<sup>13</sup> E. FULLER TORREY, SURVIVING SCHIZOPHRENIA 271 (3d. Ed. 1995).

<sup>14</sup> Murder in Families, Bureau of Just. Stat. Special Rep. (1994).

<sup>15</sup> See Christopher G. Hudson, Curtis B. Flory III, Rose Marie Friedrich, NAMI Hospital and Long Term Care Network, TRENDS IN PSYCHIATRIC HOSPITALIZATION AND LONG TERM CARE: A PLAN FOR ONGOING MONITORING AND ADVOCACY 9, 22 (1995)

<sup>16</sup> U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE, PUB. HEALTH SERVICE PUBLICATION No. 574. Patients in Mental Institutions 1955, Part II Public Hospitals for the Mentally ILL. (1956)

<sup>17</sup> SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMIN., ANN. SURV. OF ST. & COUNTY MENTAL INPATIENT SERVICES, U.S., 1996 (1998)

<sup>18</sup> For a state by state breakdown of the number of beds in state and county psychiatric hospitals, see Appendix A.

<sup>19</sup> Mr. Pataki's Public Safety Failure N.Y. TIMES, May 25, 1999, at A30

<sup>20</sup> NAMI, POLICY ON INVOLUNTARY COMMITMENT AND COURT ORDERED TREATMENT (1996, 1999)

<sup>21</sup> Rose Marie Friedrich, Curtis B. Flory, "Hope For Those Who Require Long-Term Care?, 17 NAMI ADVOCATE 13-14 (1997).

<sup>&</sup>lt;sup>2</sup> Id. <sup>3</sup> Id.

<sup>22</sup> Curtis B. Flory, Rose Marie Friedrich, "The Forgotten Population", 1 NAMI OF NEW HAMPSHIRE

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<sup>23</sup> "The hospital care received by persons with severe brain disorders moved to general care hospital psychiatric wards has been criticized. It has been characterized, in terms of constancy and quality of care, as being poorer than care in private psychiatric or even state hospitals." NAMI, IMD EXCLUSION: IMPLICATIONS OF REPEAL (1999)

Vonn Korff, M. Nestadt, G. Romanoski, *Prevalence of treated and untreated DSM-III schizophrenia*, 173 JOURNAL OF NERVOUS AND MENTAL DISEASE 577-581 (1985)
 42 U.S.C. 1396d(i)

- <sup>26</sup> An exception to the exclusion permits states to opt to receive reimbursement for persons over the age of 65 or under the age of 21.

  <sup>27</sup> E. FULLER TORREY, JOAN STEIBER, JONATHON EZEKIEL, CRIMINALIZING THE SERIOUSLY
- <sup>27</sup> E. FULLER TORREY, JOAN STEIBER, JONATHON EZEKIEL, CRIMINALIZING THE SERIOUSLY MENTALLY ILL: THE ABUSE OF JAILS AS MENTAL HOSPITALS 9-12 (1992)

<sup>28</sup> D. GALLAGHER, VOICE FOR THE MAD 24-25 (1995)

- <sup>29</sup> Steward Machine Co. v. Davis, 301 U.S. 548, 602 (1937) (McReynolds, J., dissenting)
- <sup>30</sup> "By 1880 there were 75 public psychiatric hospitals in the United states for the total population of 50 million people." CRIMINALIZING THE SERIOUSLY MENTALLY ILL: THE ABUSE OF JAILS AS MENTAL HOSPITALS 11-12.

JAILS AS MENTAL HOSPITALS 11-12.

31 The 1880 census identified 91,959 insane persons in the United States, and 58,609 persons in jails and prisons. Only 397 persons in jails and prisons were said to be mentally ill.

<sup>32</sup> See the legislative history to the Community Mental Health Centers Act of 1963, Pub. L. No. 88-164, 77 Stat. 282, 290-294 (1963), *published in* H.R. Rep. No. 694, 88th Cong., 1st Sess. (1963), *reprinted in* 1963 U.S.C.C.A.N. 1054, at 1064-66. *Id.* at 1064.

<sup>33</sup> *Id.* at 1065. <sup>34</sup> *Id.* at 1065.

- <sup>35</sup> RAEL JEAN ISAAC & VIRGINIA C. ARMAT, MADNESS IN THE STREETS 78 (The Free Press 1992) (1990)
- <sup>36</sup> 42 U.S.C. § 1396a(a)(20) (1994) and S. Rep. No. 404, 89th Cong., 1st Sess., pt. 1, at 146 (1965), *reprinted in* 1965 U.S.C.C.A.N. 1943, 2086.

Schweiker v. Wilson, 450 U.S. 221, 242 (1980) (This was a case involving a bar on SSI payments to individuals residing in IMDs.)
 HEALTH CARE FINANCING ADMINISTRATION, REP. TO CONG. MEDICAID & INST. FOR MENTAL

- <sup>3°</sup> HEALTH CARE FINANCING ADMINISTRATION, REP. TO CONG. MEDICAID & INST. FOR MENTAL DISEASES (1992) (HEREINAFTER "HCFA REPORT"), ES-3. (There is no indication in the report that HCFA made any attempt to distinguish the severely mentally ill who require hospitalization from those who can function in community-based settings.)
- <sup>39</sup> HCFA Report p. VIII-1
- <sup>40</sup> HCFA Report p. VII-4
- <sup>41</sup> THE URBAN INSTITUTE, THE MEDICAID DISPROPORTIONATE SHARE HOSPITAL PAYMENT PROGRAM: BACKGROUND AND ISSUES (1997)(HEREINAFTER DSH ISSUES) 1-2.

<sup>42</sup> 42 U.S.C. 1396r-4

- <sup>43</sup> HCFA Letter to State Medicaid Directors dated December 10, 1997.
- <sup>44</sup> 42 U.S.C. 1396r-4
- <sup>45</sup> 42 U.S.C. 1396r-4
- <sup>46</sup> Nat'l Ass'n of Psychiatric Health Sys., Policy Options: Opening the Medicaid Market For Non-Elderly Adult Services to Freestanding Psychiatric Facilities (1995)
- 47 Out of the Shadows 92
- <sup>48</sup> *Id*.
- <sup>49</sup> Out of the Shadows 104
- <sup>50</sup> BUREAU OF JUSTICE STATISTICS, 1996 SOURCE BOOK: CRIMINAL JUSTICE STATISTICS

<sup>&</sup>lt;sup>51</sup> This example is for the purposes of illustrating the effect of the IMD Exclusion. Relative costs can and do vary substantially from state to state. The example also ignores the partially offsetting effects of DSH payments.

52 NAMI, PACT ACROSS AMERICA: AN ADVOCACY STRATEGY (1996, 1999)

53 N. Wolff, T.W. Helminiak, R.J. Diamond, *Estimated societal costs of assertive mental health* 

*care*, 46 PSYCHIATRIC SERVICES 898-906 (1995)

54 OLMSTEAD v. L. C. \_\_\_\_\_ U.S. \_\_\_\_, 119 S.Ct. 2176 (1999)

55 NAMI, IMD EXCLUSION: IMPLICATIONS OF REPEAL (1996, 1999)