Department of Health and Human Services

OFFICE OF INSPECTOR GENERAL

YOUNGER NURSING FACILITY RESIDENTS WITH MENTAL ILLNESS:

An Unidentified Population

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OFFICE OF INSPECTOR GENERAL

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EXECUTIVE SUMMARY

PURPOSE

To determine the extent to which younger individuals with mental illness reside in nursing facilities.

BACKGROUND

This inspection is one in a series of Office of Inspector General reports on individuals with mental illness in nursing facilities. A companion to this report, "Younger Nursing Home Residents with Mental Illness: Pre-Admission Screening and Resident Review Implementation and Oversight" (OEI 05-99-00700) examines the admission and mental health screenings of Medicaid beneficiaries, ages 22-64, who have a serious mental illness and reside in nursing facilities. In that study we found that State implementation of Pre-Admission Screening and Resident Review (PASRR) systems, the primary mechanism by which individuals with mental illness in nursing facilities are monitored, is inadequate to identify whether younger individuals with mental illness are appropriately screened, evaluated and placed in nursing facilities.

This report attempts to ascertain the extent to which younger individuals with mental illness reside in nursing facilities. In addition, we wanted to identify the amount of Medicaid funds spent to care for this population. The national average for percentage of individuals in nursing facilities being treated for mental illness is unknown. A recent review of the National Nursing Home Surveys estimates that in 1995, there were approximately 12,000 nursing facility residents under age 65 with a primary mental illness diagnosis. We believe this figure may not accurately reflect the number of younger nursing facility residents with serious mental illness.

The 1999 Olmstead v. L.C. Supreme Court decision asserted that States are obliged to administer their services, programs, and activities to individuals with disabilities in the "most integrated setting" appropriate to their needs. Olmstead challenges States to prevent and correct inappropriate institutionalization and to review intake and admissions procedures to assure that individuals are served in the most integrated setting appropriate.

Federal Data Sources

The Health Care Financing Administration's (HCFA) Medicaid Statistical Information System (MSIS) collects claims and eligibility data for medical services reimbursed with Title XIX funds. Its purpose is to "collect, manage, analyze and disseminate information

on eligibles, recipients, utilization and payment for services covered by State Medicaid programs."

The HCFA Minimum Data Set (MDS) collects resident assessment information "to aid in the survey and certification of Medicare/Medicaid long-term care facilities and to study the effectiveness and quality of care given in those facilities." The MDS is also intended to "support regulatory, reimbursement, policy, and research functions."

To identify the number of nursing facility residents between the ages of 22 and 64 with a severe mental illness, we examined MSIS and MDS data and conducted a 51 State survey.

FINDINGS

We cannot conclusively determine the number of younger individuals with mental illness that reside in nursing facilities

After collecting data from MSIS, MDS and our 51 State survey, we cannot conclusively determine the number of younger individuals with mental illness that reside in nursing facilities. In attempting to identify this population, we encountered data inconsistencies including: the dates for which the most recent data was available; the ability to capture primary and/or secondary diagnosis; the scope of the data collected; and differing provider identification numbers for individual nursing facilities.

The HCFA data sources do not provide comparable information. Federal MSIS data for 39 States indicates that 5,745 Medicaid beneficiaries with a primary diagnosis of mental illness between the ages of 22 and 64 reside in nursing facilities. Federal MDS data indicates that 17,919 younger Medicaid beneficiaries with any diagnosis of mental illness reside in nursing facilities in these same States.

Further, HCFA data and our 51 State survey yield inconsistent results. For example, the MDS data indicates that the number of younger nursing facility residents with mental illness represents, on average, 1.6 percent of States' nursing facility populations. Our State survey indicates that for 20 States reporting this information, these residents represent, on average, 20 percent of their nursing facility populations.

The MSIS claims data cannot be validated. Only 10 of the 19 nursing facilities we visited were identified as having submitted at least one claim for younger nursing facility residents with mental illness. None of the 187 individuals whose case files we reviewed were identified in MSIS as having a Medicaid claim for nursing facility services, despite listing Medicaid as their payer source.

MSIS cannot be matched with MDS to yield reliable results for research and analysis and thus we could not discern pertinent facility level information. We were able to identify and match in MDS only 39 percent of nursing facilities that MSIS identified as having at least one younger individual with mental illness. For 10 States, none of the nursing facilities matched between MSIS and MDS.

Medicaid expenditures cannot be validated

In order to calculate States' Medicaid expenditures for younger nursing facility residents with mental illness, we had to rely on MSIS and State data. However, we believe that MSIS is an inaccurate representation and underestimation of Medicaid expenditures for this population. Medicaid expenditure data from MSIS is not validated either by our 51 State survey or our case file review. Eight States reported that they spent $30.9 million total in Federal Fiscal Year 1998 while MSIS indicated that for these eight States, total Medicaid expenditures was $15.8 million. Our survey data indicates that, on average, States spend $12.3 million per year on younger nursing facility residents with mental illness, while MSIS indicates that States, on average, spend $4.9 million per year.

States do not know where younger individuals with mental illness are receiving long-term care

Many State mental health authorities (SMHA) responding to our survey reported difficulty submitting information regarding the number of individuals with mental illness between the ages of 22 and 64 in various types of long-term care facilities. In addition, SMHAs had difficulty providing us with expenditure information. Of the 43 SMHAs that responded to our survey, only 13 were able to provide us with the complete expenditure information we requested.

State Medicaid agencies also had difficulty reporting expenditure information for all types of long-term care facilities and specifically for nursing facilities. Only 15 of 36 State Medicaid agencies were able to report Medicaid expenditures for younger nursing facility residents with a primary or secondary diagnosis of mental illness. Only nine States were able to provide us with complete expenditure figures for younger individuals with a primary diagnosis of mental illness.

OTHER CONSIDERATIONS

Our inspection focuses on younger nursing facility residents with mental illness. However, the issues we encountered regarding the validity and reliability of the data raise significant concerns about the broader use of both MDS and MSIS data in making and evaluating health care policy. Our unsuccessful attempt to identify this population is indicative of a larger problem with these Federal data sources. This examination

questions the use of Federal data sources to accurately yield important demographic, utilization, and expenditure information upon which to base policy. Without reliable information that enables us to identify populations of individuals requiring particular types of services, we cannot assess appropriateness, access and quality of care, nor determine the effectiveness of Federal Medicaid and nursing facility policy.

RECOMMENDATIONS

Recent attention on individuals with mental illness, particularly those in institutional settings, increases the need for the Health Care Financing Administration to ensure that Federal data systems can respond to both the Administration's and the public's inquiry into the status of younger nursing facility residents with serious mental illness. The HCFA should be able to use both the MSIS, MDS and other related Federal data systems to monitor the extent to which nursing facility residents have mental illness and, in turn, receive needed mental health treatment.

In order to improve the ability of HCFA and States to produce accurate nursing facility information and to increase the ability to monitor care and treatment of Medicaid nursing facility residents with mental illness, we recommend that HCFA:

- assign unique provider numbers for long-term care facilities that submit information to Federal data sources;
- provide training and clearer coding instructions to improve the ability of nursing home staff and of the MDS instrument to capture mental illness diagnoses;
- make MDS and MSIS data available in a timely manner;
- require States to report information by age; and
- require States to report information by diagnosis.

In response to the Olmstead Supreme Court Decision that requires individuals to be placed in the "most integrated and least restrictive setting appropriate," we recommend that HCFA:

- facilitate the availability of improved MSIS and MDS data to assist States in complying with HCFA's directive to identify residents and periodically review the services of all residents in Medicaid-funded institutional settings; and
- encourage States to use MSIS and MDS data systems to help demonstrate that the State has "a comprehensive, effectively working plan for placing qualified persons with disabilities in the most integrated setting appropriate."

AGENCY COMMENTS

We received comments from the Health Care Financing Administration (HCFA) and the Assistant Secretary for Planning and Evaluation (ASPE). The HCFA concurs with six of our seven recommendations. The ASPE provided general comments. Where appropriate we changed the report to reflect their comments. The full HCFA and ASPE comments are contained in Appendix A. We would like to thank HCFA and ASPE for their assistance in conducting this study and for providing us with comments.

The HCFA believes that "mental health is central to the overall well being of all our beneficiaries, including younger nursing facility residents" and that "monitoring these residents' care and treatment and maintaining accurate nursing facility information is essential to their well-being."

The one recommendation that HCFA does not concur with is amending the MDS to distinguish between primary, secondary and tertiary diagnoses. The HCFA proposes an alternative to our recommendation that would "provide training and clearer coding instructions to improve the ability of nursing home staff and of the MDS instrument to capture Mental Illness diagnoses." We agree with HCFA that providing training and improved coding instructions is in accordance with the intent of our recommendation and have changed our recommendation accordingly.

The HCFA expressed concern that the difficulty we experience in finding mental health information may be due to the timing of the study. We want to clarify that our methodology did not rely on information captured exclusively by an initial MDS assessment. Instead, both our reviews of MDS initial and quarterly assessments of individual medical files and of the MDS database universe for a six month period would have enabled us to capture mental health diagnoses.

The HCFA reports that they have concerns that our inspection does not accurately depict their role in determining State compliance with the Olmstead Decision. What we wanted to emphasize was that improved MSIS and MDS data systems can help facilitate States' compliance with the Olmstead Decision as part of a multi-faceted approach. We agree that the improvements HCFA has committed to making should prove to be beneficial.

The ASPE expressed concern that the focus of our report, younger individuals with serious mental illness, comprise less than 3% of nursing home residents according to the 1996 Medical Expenditure Panel Survey (MEPS). We believe that there is not a reliable source of information to determine this population. More importantly, we continue to believe that regardless of the overall size of the national population of younger nursing facility residents with serious mental illness, their presence and care in nursing facilities warrants HCFA's specialized attention.

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BACKGROUND

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De-Institutionalization

Between 1955 and 1985, many large State mental institutions closed, reducing by 80 percent States' institutionalized population of individuals with mental illness. De-institutionalization changed the health care delivery system for individuals with mental illness and challenged States and communities to identify alternative treatment options for individuals with mental illness. The national focus shifted to rehabilitating individuals with mental illness in community-based programs, tailored to a wide variety of needs.

However, in many communities, de-institutionalization accelerated without the creation of local programs commensurate with the population requiring placement. According to the 1999 "Mental Health: A Report of the Surgeon General," community care and de-institutionalization programs were implemented without evidence of effectiveness and needed services are not always available.

Individuals with Mental Illness in Nursing Facilities

The Pre-Admission Screening and Resident Review (PASRR) mandated by the Omnibus Budget Reconciliation Act of 1987 targets nursing facility applicants and residents with a

probable mental illness diagnosis for mandatory psychiatric evaluation. This process was designed to divert psychiatric patients from nursing facilities and prevent the inappropriate admission and retention of people with mental disabilities, thereby eliminating the use of nursing homes for individuals with chronic mental illness. In addition, PASRR was intended to identify residents in need of more appropriate acute treatment in hospitals or long-term treatment in community based settings,[1] and to improve the accountability of nursing facilities for the appropriate management of psychiatric disorders in their residents.[2] We examined the PASRR and the safeguards that monitor the admission and mental health treatment of younger Medicaid beneficiaries who have a serious mental illness and reside in nursing facilities in a companion report.[3]

Nursing facilities have traditionally been "the last refuge" for individuals with mental illness. Individuals with mental illness may find themselves in a nursing facility because of physical and behavioral problems, the lack of caretakers, or insufficient community services, including long-term care."[4] The availability of necessary mental health treatment for nursing home residents with mental illness has long been a concern. A 1986 Institute of Medicine report suggests that patients with severe mental illness de-institutionalized from State mental hospitals were being discharged to nursing homes that could not provide the specialized services they needed."[5]

In addition, experts believe that the placement of non-elderly residents with mental illness in nursing facilities with elderly residents raises questions regarding the ability of nursing facilities to provide appropriate care to both populations. There are significant differences between the needs of the geriatric population and younger adults with mental illness who reside in nursing facilities. There is also concern regarding the lack of mental health training and experience of typical nursing facility staff.

Nursing facility residents with serious and persistent mental illness

The national average for percentage of individuals in nursing facilities being treated for mental illness is unknown. A recent review of the National Nursing Home Survey (NNHS) indicates that nationally, in 1995, there were 70,000 residents in nursing

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1 Surgeon General Report 1999

2 Journal American Geriatric Society 45:1173-1181, 1997.

3 "Younger Nursing Home Residents with Mental Illness: Pre-Admission Screening and Resident Review" (OEI-05-99-00700)

4 Psychiatric Services 51:354-358, March 2000. American Psychiatric Association

5 Psychiatric Services, February 1998, Vol 49, No. 3, p. 229-233.

facilities with a primary mental illness diagnosis.[6] The review estimates that there are between 8,000 to more than one million residents of nursing facilities with a mental illness, including individuals with dementias, depression and schizophrenia -- with and without comorbidities. The report emphasizes that further subclassification is needed to produce a better estimate since the clinical and social policies to deal with mental illness, with and without physical comorbidity, are quite different. The NNHS review estimates that there are approximately 12,000 nursing facility residents with severe mental illness under age 65. [7] We believe this figure may underestimate the number of younger nursing facility residents with serious mental illness.

The Olmstead Decision

The 1999 Olmstead v. L. C. Supreme Court decision asserted that continued institutionalization may violate the rights of an individual with mental illness or mental retardation under Title II of the Americans with Disabilities Act. The Supreme Court interpreted Title II to oblige States to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[8]

Title II gives an individual the right to live in the most appropriate community integrated setting. States are required to provide community-based services for persons with disabilities when the State's treatment professionals determine that such placement is appropriate. States must take into consideration their resources and the needs of other people with mental disabilities in making such determinations.

The Olmstead Decision challenges States to "prevent and correct inappropriate institutionalization and to review intake and admissions processes to assure that persons with disabilities are served in the most integrated setting appropriate." In response to the Olmstead Decision, the Department issued a letter to all governors in January 2000, stating that "no person should have to live in a nursing home or other institution if he or she can live in his or her community." Moreover, the Department said that "unnecessary institutionalization of individuals with disabilities is discrimination under the Americans with Disabilities Act."[9]

Recently, the Health Care Financing Administration (HCFA) sent a letter to State Medicaid Directors because "Medicaid programs play a critical role in making

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6 Psychiatric Services 51:354-358, March 2000. American Psychiatric Association.

7 Psychiatric Services 51:354-358, March 2000. American Psychiatric Association.

8 28 CFR 35.130(d)

9 New York Times, February 13, 2000

community services available." The HCFA informed the States that under the Court's decision, States are required to provide community-based services for persons with disabilities when the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others who are receiving State-supported disability services.[10] The HCFA has interpreted the ruling to mean that a State waiting list for services that moves reasonably well can be considered in compliance with the decision. State Medicaid directors are encouraged to periodically review the services of all residents in Medicaid-funded institutional settings.

Surgeon General's Report

Additional recent attention to the care of individuals with mental illness in nursing facilities was brought about by the "Mental Health: A Report of the Surgeon General" which states that there are "major barriers that prevent the delivery of appropriate care to residents of nursing facilities who have mental illness."[11] Researchers have found that, despite a high prevalence of individuals with mental illness residing in nursing facilities, these facilities are ill-equipped to meet their needs.[12] The report also states that "Medicaid policies discouraged nursing facilities from providing specialized mental health services, and Medicaid reimbursements for residents have been too low to provide a strong incentive for participation by highly trained mental health providers."[13]

Funding and State Responsibility for Treating Individuals with Mental Illness

Historically, States have primary responsibility for funding the treatment of persons with mental illness. However, during the past two decades, the role of direct State funding of mental health care has been reduced, whereas Medicaid funding of mental health care has grown in importance. Despite the Federal Government's current larger financial investment in mental health services, Medicaid and Medicare impose limitations on coverage for the long-term care of individuals with mental illness. These coverage limitations are intended to reinforce States' primary responsibility for this population.

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10 State Medicaid Director Letter January 14, 2000

11 Mental Health: A Report of the Surgeon General, p. 374

12 Lombardo, N.E. *Barriers to mental health services for nursing home residents*. Washington, DC: American Association of Retired Persons, 1994.

13 Surgeon General Report 199, p. 374.

In particular, Medicaid will not pay for services provided in an institution for mental disease (IMD) for individuals ages 22 to 64.[14] The Social Security Act defines an IMD as "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."[15] Medicaid will pay for the care of individuals with mental illness in nursing facilities where 50 percent or less of the facility's beds were filled by residents with mental illness.[16]

According to the Surgeon General's report, the estimated number of psychiatric residents of all ages treated in nursing facilities has significantly increased, based on the record level of Medicaid and Medicare bills for treatment of mental illnesses. In 1996, treatment costs of individuals with mental illness was $66.7 billion.[17] Medicaid comprised 19 percent of total expenditures on mental health treatment ($13 billion).[18] Care for persons with mental illness residing in nursing facilities accounted for $4.7 billion (7.1%) of total mental health expenditures ($69 billion).

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14 Social Security Act Section §1905 (h)(I)(C) provides that the 21st birthday is the cut off point for benefits unless the beneficiary is under psychiatric care prior to and following their 21st birthday in which case they may continue to receive covered care until recovery or their 22nd birthday, whichever comes first. For purpose of this report, in order to avoid confusion,, we reviewed individuals ages 22 to 54.

15 Social Security Act Section §1905 (h)(2)(I)

16 1981 Medicaid ruling

17 Health Care Financing Administration (HCFA) 1996 estimates of national health expenditures

18 "Mental Health: A Report of the Surgeon General" 1999

Mental Health Expenditures by Payer 1996

	Percent of total MH Expenditures	MH Expenditures (in billions)	Percent of all health care expenditures for this category
PRIVATE PAY	**47%**	**$32.43**	**6%**
Private insurance	27%	$18.63	6%
Out of pocket	17%	$11.73	6%
Other private pay	3%	$2.07	5%
PUBLIC PAY	**53%**	**$37.00**	**8%**
Medicaid	19%	$13.00	9%
State/Local	18%	$12.42	18%
Medicare	14%	$10.00	5%
Other Federal (VA, DoD, SAMHSA Block Grants)	2%	$1.38	3%

Source: Mental Health: A Report of the Surgeon General

Federal Budget:

Substance Abuse and Mental Health Services Administration	$2.5 billion (FY1999)
Center for Mental Health Services	$0.5 billion (FY1999) [34% discretionary, 66% block grants]
National Institute of Mental Health	$0.9 million (FY1999)
Medicaid mental health	$13.11 billion (1996)
Medicare mental health	$9.66 billion (1996)

Federal Data Sources

MSIS

The purpose of the Medicaid Statistical Information System (MSIS) is to "collect, manage, analyze and disseminate information on eligibles, recipients, utilization and payment for services covered by State Medicaid programs." States provide HCFA with quarterly computer files containing specified data elements for: (1) persons covered by Medicaid (Eligible files); and, (2) adjudicated claims (Paid Claims files) for medical services reimbursed with Title XIX funds. These data files are furnished quarterly according to the Federal Fiscal Year (FY) schedule. The MSIS is used by HCFA to produce Medicaid program characteristics and utilization information for the States. The MSIS data files also provide HCFA with a large-scale database of State eligibles and services for other analyses. Prior to FY 1999, MSIS was a voluntary program. However, in accordance with the Balanced Budget Act of 1997, all claims processed on or after January 1, 1999 must be submitted electronically in the MSIS format.

MDS

The Federal Minimum Data Set (MDS) was established to "aid in the administration of the survey and certification of Medicare/Medicaid long-term care facilities and to study the effectiveness and quality of care given in those facilities." The MDS was also designed to "support regulatory, reimbursement, policy, and research functions, and enable regulators to provide long-term care facility staff with outcome data for providers' internal quality improvement activities." Federal MDS information is collected daily from all nursing facilities for all residents, regardless of payer source. The MDS assessment cycle, which captures information on admission, discharge and when a change in health status occurs, is collected quarterly.

SCOPE

This report evaluates Federal and State data used to identify the mental illness diagnosis of nursing facility residents, the numbers of nursing facility residents with a mental illness diagnosis, as well as expenditures for this population. We focused our study on Medicaid residents of nursing facilities between the ages of 22 and 64 with a "severe and persistent mental illness" as their primary or secondary diagnosis. We did not evaluate residents with Alzheimers's disease, dementia or organic brain disorders. We focused on this population because we believe there are fundamental features of care and protection unique to younger persons with severe and persistent mental illness residing in the nursing facilities.

We produced a companion report, "Younger Nursing Home Residents with Mental Illness: Pre-Admission Screening and Resident Review Implementation and Oversight" (OEI 05-99-00700) which evaluates the safeguards that monitor the admission and mental health treatment of Medicaid beneficiaries, ages 22-64 who have a serious mental illness and reside in nursing facilities.

METHODOLOGY

For the 39 States that submitted Medicaid claims and eligibility information to HCFA's Medicaid Statistical Information System during the 4th quarter of 1998, we attempted to identify the number of nursing facility residents between the ages of 22 and 64 with a primary diagnosis of severe mental illness that had a Medicaid claim.

We analyzed the Minimum Data Set from January through June 1999, to discover how many Medicaid resident assessments for residents ages 22 to 64 indicated a mental illness diagnosis.

We conducted a national survey of 50 State Mental Health, Medicaid and Medicare/ Medicaid Survey agencies and State Long-Term Care (LTC) Ombudsmen and the District of Columbia, henceforth referred to as the "51 State Survey," to understand the extent to which nursing facilities in each State provide care for persons ages 22 to 64 with a major mental illness diagnosis from the International Classification of Diseases, 9th Revision (ICD-9) codes 293-301, 311, 312. We also received State and Medicaid mental health treatment expenditures for this population. In addition, we surveyed States to determine in what other types of long-term care settings younger individuals with mental illness reside and State expenditures in those settings.

We received 131 surveys from 50 States:

- 43 from State mental health authorities,
- 36 from Medicaid agencies,
- 29 from State Medicare/Medicaid Survey agencies, and
- 23 from the State LTC Ombudsmen.

We made onsite visits to five States — California, Florida, Kansas, Minnesota and Pennsylvania to conduct State agency interviews, visit nursing facilities and conduct case file review. We selected these States based on:

- the high percentage of residents with a mental illness as their primary or secondary diagnosis in individual nursing facilities as identified by the Federal Online Survey and Certification Reporting System (OSCAR) data;
- their submission of data to MSIS in FY 1998[19]; and
- geographic location.

In each of the five case study States, we selected four nursing facilities based on the high percentage of residents ages 22-64 with a primary or secondary diagnosis of mental illness being cared for in that facility, as well as geographic proximity. In the 5 case study States, we visited 19 nursing facilities and reviewed 187 resident case files of current nursing facility Medicaid residents between the ages of 22 and 64 with a major mental illness diagnosis from the International Classification of Diseases, 9th Revision (ICD-9) codes 293-301, 311, 312. We selected the files to review either through a random sample of a specific nursing facility's population of younger individuals with serious mental illness or where time permitted, a review of all residents whose age and diagnosis qualified them to be part of our study population.

We conducted our review in accordance with the Quality Standards for Inspections issued by the President's Council on Integrity and Efficiency.

[19] All 5 States we visited submitted data to the Federal MSIS as of 1998.

F I N D I N G S

We cannot conclusively determine the number of younger nursing facility residents with mental illness

Federal Intent for Data Sources

According to HCFA, the individual paid claims and eligibility information that is captured by the Medicaid Statistical Information System (MSIS) are used for program analysis and national research on Medicaid populations and expenditures. The HCFA indicates that current uses of MSIS data include health care research and evaluation activities; program utilization and expenditures forecasting; analyses of policy alternatives; responses to congressional inquiries; and matches to other health related databases.[20]

The Minimum Data Set (MDS), HCFA's database on nursing facility resident assessments was established, in part, to study the effectiveness and quality of care given in that setting. The MDS was designed to "support regulatory, reimbursement, policy, and research functions" and "provide outcome data for providers."[21]

Using both the MSIS and MDS, we attempted to ascertain the extent to which younger individuals with mental illness reside in nursing facilities. In addition, we wanted to identify the amount of Medicaid funds spent to care for this population. In order to fill any gaps and to validate the data provided by MSIS and MDS, we conducted a 51 State, 4 agency survey and collected data from our site visit case file review. Specifically, we wanted to identify the following characteristics of States' nursing facility populations:

- the total number of younger individuals with mental illness residing in nursing facilities;
- the percent of States' nursing facility populations that are younger individuals with mental illness;
- the total number of States' nursing facilities that care for younger individuals with mental illness;
- the percent of States' nursing facilities that care for younger individuals with mental illness; and

[20] HCFA Website

[21] HCFA Website

- in nursing facilities that have at least one younger resident with mental illness, how many and what percent (on average) of the nursing facility population are younger individuals with mental illness.

Data inconsistencies

In using different Federal data sources, we encountered inconsistencies including:

- the dates for which the most recent data was available;
- the manner in which a younger individual with mental illness could be identified, i.e. matching diagnosis to claims or to resident assessments;
- the capability to capture primary and/or secondary diagnosis;
- the scope of the data collected, i.e. for how many States data was available; and
- different provider identification numbers, i.e. the lack of unique provider identifiers for a specific facility.

The table below highlights the differences between the two data sets and the data captured in our survey and case file review.

Data sources & Data captured

Data Source	Time Period	States Included	Manner data collected	Capability of capturing mental illness diagnosis
MSIS	Fourth Quarter 1998	39	Voluntary	Primary Only
MDS	January - June 1999	All 50 States & Territories	NF Reported	ALL diagnoses
State Survey	Federal FY 1998	33	State reported	Primary AND/OR Secondary
Case file review	February/March 2000	5	OEI collected	ALL diagnoses

Data is inconclusive

After collecting data from the above identified sources, we cannot conclusively determine the extent to which younger individuals with mental illness reside in nursing facilities. Federal MSIS data for 39 States indicates that in fourth quarter FY 1998, 5,745 Medicaid beneficiaries residing in nursing facilities are between the ages of 22 and 64 and have a primary diagnosis of mental illness. This number represents only 32 percent of the population of younger individuals with mental illness that are identified in MDS, for the same 39 States. The MDS data for January through June of 1999 yields an unduplicated

count of 17,919 younger nursing facility residents with any diagnosis of mental illness in the 39 States. In all States and Territories, an unduplicated count in MDS indicates that there were 45,710 younger, Medicaid nursing facility residents with mental illness.

According to MDS, on average, younger individuals with mental illness represent 1.6 percent of States' nursing facility populations. This information is inconsistent with our survey data. Twenty State mental health authorities (SMHAs) reported a total of 40,277 younger nursing facility residents with mental illness. These 20 States report that, on average, 10 percent of a State's nursing facility population is comprised of younger individuals with a primary diagnosis of mental illness, and 20 percent is comprised of younger individuals with a primary **or** secondary diagnosis of mental illness. Our case file review of 19 nursing facilities indicated that approximately 14 percent of these nursing facility residents were younger individuals with a primary or secondary diagnosis of mental illness.

The table below demonstrates that data inconsistencies prevent us from making a definitive assessment of the total number of younger nursing facility residents with mental illness.

Total Number and Percent of Younger Individuals with Mental Illness in Nursing Facilities

	MSIS[22] (34 States)	MDS[23] (39 States)	State Reported Data (20 States)[24]	Case File Review (19 Facilities)
Total Number of NF Residents	NR	1,101,599	--	2,712
Number of Younger Individuals with MI Residing in NFs	5,745	17,919	40,277	385
Percent of NF Residents that are Younger Individuals with MI	--	1.6%	--	14.2%
Average Number of Younger Individuals w/ Mental Illness Residing in NFs in a State	169	459	2,014	--
Average % States' NF Population of Younger Individuals with Mental Illness	--	1.6%	10%[25]	--

NR = Not Requested

22 MSIS data for 34 of the 39 MSIS States. 5 States did not submit this information to HCFA.

23 MDS data for the 39 States that submitted information to MSIS.

24 20 State mental health authorities reporting

25 Unweighted average of percentages reported by 18 State Medicaid agencies

Claims data cannot be validated

We attempted to validate the MSIS expenditures by identifying in the MSIS claims and eligibility files the 19 nursing facilities we visited and the 187 younger Medicaid beneficiaries with mental illness whose files we reviewed. Only 10 of the 19 nursing facilities were identified as having submitted at least one claim for younger individuals with mental illness. To identify individual claims for nursing facility residents, we attempted to identify the 187 individuals whose case files we reviewed. None of these residents were found in MSIS, even though 111 were admitted to the nursing facility in 1998 or prior and had indicated Medicaid as their payer source.

Matching data sources yields unreliable results

Contrary to HCFA's assertion, MSIS cannot be matched with MDS to yield reliable results for research and analysis. As a result, we could not discern valuable facility level information. We attempted to identify the average percent of a nursing facility's total population with a mental illness between the ages of 22 and 64. To do so, we planned to use MDS to provide the total population of the nursing facility, while MSIS would provide us with the number of individuals with mental illness between the ages of 22 and 64. Then, we planned to cross the provider numbers of MSIS and MDS to identify the average percent of a nursing facility's total population with a mental illness between the ages of 22 and 64 for each of the 34 States that submitted information to MSIS.

However, we were only able to identify and match with MDS 39 percent of nursing facilities that MSIS identified as having at least one younger individual with mental illness. The percent of nursing facility matches between MSIS and MDS ranges from 0 to 92 percent in the 39 reporting States. For 10 States, none of their nursing facilities matched with the MDS nursing facility identifiers. Therefore, we cannot say with any certainty what percent of nursing facility residents, on average, are younger individuals with mental illness.

Our inability to match the providers in these two HCFA data sources can be partially attributed to the lack of a unique provider number for each nursing facility. The inability to match nursing facility data from MSIS and MDS has ramifications for obtaining reliable information regarding nursing homes overall. States frequently assign facilities different numbers when submitting information to different Federal data sources. The MSIS provider numbers are often different than the MDS provider number assigned to a facility for the Minimum Data Set. A given provider may have one number for MSIS, another for MDS, another for OSCAR, and yet another for Social Security and Internal Revenue Service tax purposes. In addition, States may assign a new provider number when there is a change in nursing facility ownership.

State survey difficulties

State survey respondents indicated that they had difficulty providing the information we requested regarding younger individuals with mental illness in nursing facilities. Many States were unable to respond to our information request because they do not collect or sort data by age. In addition, Medicaid and Survey Agencies in 20 States reported that they could not distinguish data by primary and secondary diagnosis. Two States also indicated that secondary diagnosis is not incorporated into their central database.

A few States expressed frustration with the MDS system, reporting that it is incomplete and that it does not break out diagnosis by primary or secondary diagnosis so that they could not use these data to respond to our survey. Three State agencies stated that information was unavailable because the MDS is incomplete. One State indicated that they would like to use MDS for identifying this population but they know that MDS lacks the necessary data.

Medicaid expenditures cannot be validated

To calculate States' Medicaid expenditures for younger nursing facility residents with mental illness, we had to rely on MSIS and State data -- MDS does not collect expenditure information other than resident's payer source. We believe however, that MSIS is an inaccurate representation and underestimation of Medicaid expenditures for this population.

As discussed above, MSIS does not accurately account for the number of younger individuals with mental illness who submit a Medicaid claim for nursing facility services. In addition, MSIS captures claims and eligibility information matched to a specific diagnosis code. A nursing facility claim for per diem might not identify an individual with a serious mental illness if it is not his/her primary diagnosis. Therefore, this data underestimates State and Federal expenditures for this population.
Medicaid expenditure data from MSIS is not validated by our survey and case file review. There is a discrepancy in the Medicaid expenditures identified through MSIS and in our State survey. Eight States that responded to our survey provided Medicaid expenditures for younger nursing facility residents with a primary diagnosis of mental illness also submitted claims to MSIS. These eight States reported that they spent, in total, $30.8 million in Medicaid dollars in Federal FY 1998.

However, this figure is twice the amount indicated by MSIS data for this population in these same eight States. The MSIS data indicates that the total Medicaid expenditure for the eight States was approximately $15.7 million for Federal FY 1998 ($3.9 million for

4th Quarter 1998). [26] Further, our survey data indicates that on average States spent $3.1 million for one quarter, or $12.3 million for one year, on younger nursing facility residents with mental illness.[27] However, MSIS data indicates that, on average, States spend $1.2 million per quarter on this population, approximately $4.9 million per year.

States do not know where younger individuals with mental illness are receiving long-term care

State mental health authorities

State mental health authorities (SMHA) responding to our national survey report that individuals with mental illness, ages 22-64, reside in a variety of long-term care facility settings. However many of the SMHAs that responded to our survey reported that they had difficulty reporting the number of individuals in this specific age group residing in the types of facilities outlined in the chart below. Many States could not provide us with this information as they do not report by age. Twelve States report that facility level information was unavailable. Four States were only able to provide long-term care facility health information for all ages.

Long-Term Care Options for Younger Individuals with Mental Illness

Type of Long-term Care Facility	States Reporting	Residents (Total)	Residents (Average)
IMD's	14	141,825	10,130
State Psychiatric Hospitals	27	75,971	2,814
Community-Based Facilities	17	44,069	2,592
Hospital Psychiatric Wards	11	89,707	8,155
Nursing Facilities	20	40,277	2,014
Other[28]	8	34,505	4,313

Source: 51 State Mental Health Authority Survey

[26] For all 39 States MSIS data indicates that for 4th Quarter 1998 $41.6 million (or $166.4 million for the year) Medicaid dollars were spent on mental health claims for younger individuals with mental illness in nursing facilities.

[27] Thirteen States reporting.

[28] "Other" includes assisted living, board and care or personal care homes.

Many States that responded to our survey were not able to provide all of the expenditure information we requested. Of the 43 State mental health authorities that responded to our survey, only 13 were able to provide us with expenditures from all of the funding sources we requested.[29] For these 13 States, the total mental health expenditure is $2.4 billion. On average, State funds accounted for 69.2 percent of total mental health expenditures for these States.

State Mental Health Expenditures Reported by 13 States

Funding Source	Total Dollars	Average % of Total MH
State Funds	$1.4 billion	69.2%
SAMHSA Block Grants	$143.9 million	4.8%
Specialized Services	$57.8 million	1.5%
Other	$886 million	37.1%
Total	$2.4 billion	

Source: 51 State Mental Health Agency Survey

Medicaid Agencies

State Medicaid agencies also had difficulty reporting expenditure information for all types of long-term care facilities and specifically nursing facilities. Most State Medicaid agencies did not report expenditure information for the types of long-term care facilities where younger individuals with serious mental illness may reside. Only 15 of 36 State Medicaid agencies were able to report Medicaid expenditure for younger nursing facility residents with a primary or secondary diagnosis of mental illness. These 15 States report spending a total of $466.3 million in Medicaid funds for this population.

Only nine States were able to provide complete expenditure information for younger individuals with a primary diagnosis of mental illness. In total, these nine States spent $426.8 million in Medicaid funds on individuals of all ages with a primary diagnosis of mental illness in all types of facilities. The same nine States reported that, in total, they spent $29.8 million in Medicaid funds on younger nursing facility residents with a primary diagnosis of mental illness and $125.7 million for this population in all types of long-term care facilities.

[29] Of the 43 State mental health authorities that responded to our survey 35 were able to report dollars from State funds, 33 were able to report SAMHSA block grant dollars, and only 22 States were able to report specialized service dollars.

Medicaid Expenditures for Individuals with a Primary Mental Illness Diagnosis

	Ages 22-64 in nursing facility	Ages 22-64 in all long-term care facilities	All ages in all long-term care facilities
9 States	$29.8 million	$125.7 million	$426.8 million

Source: 51 State Survey, 2000, Fiscal Year 1998

OTHER CONSIDERATIONS

Our inspection focuses on younger nursing facility residents with mental illness. However, the issues we encountered regarding the validity and reliability of the data raise significant concerns about the broader use of both MDS and MSIS data in making and evaluating health care policy. Our unsuccessful attempt to identify this population is indicative of a larger problem with these Federal data sources. This examination questions the use of Federal data sources to accurately yield important demographic, utilization, and expenditure information upon which to base policy. Without reliable information that enables us to identify populations of individuals requiring particular types of services, we cannot assess appropriateness, access and quality of care, nor determine the effectiveness of Federal Medicaid and nursing facility policy.

RECOMMENDATIONS

Recent attention on individuals with mental illness, particularly those in institutional settings, increases the need for HCFA to ensure that Federal data systems can respond to both the Administration's and the public's inquiry of the status of younger nursing facility residents with serious mental illness. In response to both the "Mental Health: A Report of the Surgeon General" and the Olmstead Supreme Court Decision, the Administration has focused attention on ensuring the appropriate care of individuals with mental illness in nursing facilities and the fact that "no person should have to live in a nursing home or other institution if he or she can live in his or her community."

The HCFA and others should be able to use both MSIS, MDS and other related Federal data systems to monitor the extent to which nursing facility residents have mental illness and, in turn, receive needed mental health treatment. Instead, the use of Federal MSIS and MDS data to identify younger individuals with mental illness is limited by the lack of a unique provider identifier to cross and match providers in more than one data source, the lack of available data that is timely, the time differential in available data from these two sources, and the type of data collected. The MSIS is primarily used by HCFA for beneficiary enrollment information, while States use MDS to provide information to State survey agencies and individual facilities.

Effective MSIS and MDS data systems can better ensure that barriers which prevent the necessary care provided to all residents of nursing facilities are being systematically evaluated and, in turn, eliminated. The HCFA must ensure that MSIS and MDS data systems produce comprehensive, consistent, valid, reliable and accurate information in order to facilitate the identification of nursing facility residents both within and across individual databases in order to provide a comprehensive picture of how nursing facility residents are affected by current policies.

In order to improve the ability of HCFA to produce accurate nursing facility information and to monitor the care and treatment of Medicaid nursing facility residents, we recommend that HCFA:

- assign unique provider numbers to long-term care facilities that submit information to Federal data sources;
- provide training and clearer coding instructions to improve the ability of nursing home staff and of the MDS instrument to capture mental illness diagnoses
- make MDS and MSIS data available in a timely manner;
- require States to report information by age; and
- require States to report information by diagnosis.

In response to the Olmstead Supreme Court Decision that requires individuals to be placed in the "most integrated and least restrictive setting appropriate," we recommend that HCFA:

- facilitate the availability of [improved] MSIS and MDS data to be used to assist States in complying with HCFA's directive to identify residents and periodically review the services of all residents in Medicaid-funded institutional settings; and

- encourage States to use MSIS and MDS data systems to demonstrate that the State has "a comprehensive, effective working plan for placing qualified persons with disabilities in the most integrated setting appropriate."

AGENCY COMMENTS

We received comments from the Health Care Financing Administration (HCFA) and the Assistant Secretary for Planning and Evaluation (ASPE). The HCFA concurs with six of our seven recommendations. The ASPE provided general comments. Where appropriate we changed the report to reflect their comments. The full HCFA and ASPE comments are contained in Appendix A.

The HCFA believes that "mental health is central to the overall well being of all our beneficiaries, including younger nursing facility residents" and that "monitoring these residents' care and treatment and maintaining accurate nursing facility information is essential to their well-being." We would like to thank HCFA for their assistance in conducting this study and for providing us with substantive and insightful comments.

The one recommendation that HCFA does not concur with is amending the MDS to distinguish between primary, secondary and tertiary diagnoses. The HCFA proposes an alternative to our recommendation that would "provide training and clearer coding instructions to improve the ability of nursing home staff and of the MDS instrument to capture Mental Illness diagnoses." Specifically, HCFA proposes including a clarification of the coding requirements surrounding completion of the Diagnoses section of the MDS and in particular, capturing mental illness diagnoses. The Manual revision is planned for Spring 2001. Our intent to making changes in the MDS is to enhance nursing facilities' ability to capture serious mental illness regardless of the ranking of diagnosis and increase nursing facilities' ability to identify and accurately care plan for younger residents with any serious mental illness. We agree with HCFA that providing training and improved coding instructions is in accordance with the intent of our recommendation and have changed our recommendation accordingly.

The HCFA expressed concern that the difficulty we experience in finding mental health information may be due to the timing of the study. In particular, concern was expressed that we were looking for diagnostic information not required to be included in the MDS database at the time of our study. We want to clarify that our methodology did not rely on information captured exclusively by an initial MDS assessment which before its latest iteration may not have included relevant mental health information. Instead, we reviewed medical files of individuals with serious mental illness that included both their initial MDS assessment and at least two quarterly MDS assessments which would have captured their mental illness diagnosis had it been accurately recorded by the nursing facility. In addition, our review of the MDS database universe for a six month period allowed us to capture both the initial and at least one quarterly MDS assessment which, again would have enabled us to capture mental health diagnoses.

The HCFA reports that they have concerns that our inspection does not accurately depict their role in determining State compliance with the Olmstead Decision. What we wanted to emphasize was that improved MSIS and MDS data systems can help facilitate States' compliance with the Olmstead Decision as part of a multi-faceted approach. We agree that the improvements HCFA has committed to making should prove to be beneficial.

The ASPE expressed concern that the focus of our report, younger individuals with serious mental illness, comprise less than 3% of nursing home residents according to the 1996 Medical Expenditure Panel Survey (MEPS). The MEPS bases this particular figure on information gathered from the MDS. Again, as we point out in our report, the MDS is not a reliable data source for a variety of reasons. Further, in 1996, when the MEPS was released, the ability to capture mental illness diagnosis through the MDS was even more limited than the time period we reviewed.

In addition, ASPE states that the MDS and MSIS are difficult to compare because they capture different diagnostic information. We agree with ASPE that MDS and MSIS are difficult to compare which contributed to our inability to accurately quantify this population. More importantly, we continue to believe that regardless of the overall size of the national population of younger nursing facility residents with serious mental illness, their presence and care in nursing facilities warrants HCFA's specialized attention.

We would like to thank ASPE for providing us with comments.

APPENDIX A

Agency Comments

DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Care Financing Administration

The Administrator
Washington, D.C. 20201

DATE: OCT 31 2000

TO: June Gibbs Brown
Inspector General

FROM: Michael M. Hash
Acting Administrator

SUBJECT: Office of Inspector General (OIG) Draft Report: "Younger Nursing Facility Residents with Mental Illness: An Unidentified Population," (OEI-05-99-00701).

Thank you for the opportunity to comment on the draft report. This report is a companion to a previous OIG report, "Younger Nursing Facility Residents with Mental Illness: Preadmission Screening and Resident Review Implementation and Oversight," (OEI-05-99-00700).

Mental health is central to the overall well-being of all our beneficiaries, including younger nursing facility residents. Monitoring these residents' care and treatment, and maintaining accurate nursing facility information is essential to their well-being. HCFA maintains two important databases, the Minimum Data Set (MDS) and the Medicaid Statistical Information System (MSIS) that help us monitor care and maintain accurate nursing facility information. MDS information is collected each day from nursing homes for all residents. It assists in the administration of survey and certification of Medicare and Medicaid nursing homes. MSIS is a set of data that HCFA uses to maintain and track Medicaid enrollment and utilization. The information contained in MSIS is sent to HCFA from the States.

Because data needs typically evolve, both MDS and MSIS require updates and revisions. HCFA is continually working to improve the content and availability of these databases. For example, HCFA recently began work on a draft MDS version 3.0, and we are considering the recommendations in this report as we refine this version. HCFA also is developing user-friendly software to facilitate use of MSIS data with completion expected by late Spring 2001

In addition, I want to point out that ensuring nursing home residents have safe, quality care is a priority for HCFA. As you know, in 1995, the Department of Heath and Human Services issued the toughest nursing home enforcement regulations in the history of Medicare and Medicaid. After implementing those reforms and monitoring the results,

Agency Comments

the Administration launched an expanded nursing home initiative in July 1998 to further assure that nursing home residents receive quality care. As part of the ongoing commitment, HCFA requires states to crack down on homes that repeatedly violate health and safety standards. Under these efforts, and additional actions we have taken in hospitals and in other provider settings, we are continually working to improve the lives of nursing home residents and all our beneficiaries with mental illness. Our efforts are achieving results. For example in nursing homes, physical restraint use dropped from 16.3 to 11.1 percent from 1997 to 1999.

Finally, although it is vital for HCFA to produce accurate nursing facility information and to monitor the care and treatment of nursing facility residents, we have some concerns that the draft report does not accurately depict HCFA's role in determining State compliance with the Supreme Court's Olmstead decision. Our response to the recommendations and our technical comments are attached.

Attachment

HCFA Response to OIG Recommendations in
"Younger Nursing Facility Residents
with Mental Illness: An Unidentified Population"

1) **In order to improve the ability of HCFA to produce accurate nursing facility information and to monitor the care and treatment of Medicaid nursing facility residents, we recommend that HCFA:**

- **Assign unique provider numbers to long-term care facilities that submit information to Federal data sources**

  We concur, but State compliance is contingent on implementation of the Health Insurance Portability and Accountability Act (HIPAA). At present, unique Medicare provider numbers are federally assigned while States assign Medicaid provider numbers. Currently, the Medicaid Statistical Information System (MSIS) accepts whatever provider numbers the States submits. States may use their own State-specific provider numbers until HIPAA is implemented. At that point, facilities will have unique Medicare and Medicaid provider numbers that will address the OIG's recommendation.

- **Amend MDS to distinguish between primary, secondary, tertiary diagnoses**

  We do not concur. If the goal is improving the extent to which facilities capture current mental illness diagnoses on the Minimum Data Set (MDS), the resolution should be a matter of training emphasis, rather than addition of new data elements. We are publishing a series of Questions & Answers and coding clarifications for MDS items is planned for Spring 2001. We propose including a clarification of the coding requirements surrounding completion of the Diagnoses section of the MDS and in particular, capturing mental illness diagnoses.

  Further, HCFA also suggests changing the language in this recommendation from "amend the MDS to distinguish between primary, secondary and tertiary diagnoses" to language such as "provide training and clearer coding instructions to improve the ability of nursing home staff and of the MDS instrument to capture Mental Illness diagnoses." The suggested language clarifies the goal - to accurately capture Mental Illness diagnoses on the MDS.

  We also want to note that, for their study, the OIG relied in part on information contained in MDS Item AB 9 "Mental Health History." This data item indicates the presence of any history of mental retardation, mental illness, or developmental disability. Collection of this particular piece of

historical information is required only on admission. At the time MDS automation and electronic transmission requirements were implemented, nursing homes had already been collecting MDS data internally for about eight years. HCFA required transmission of all assessments completed from the implementation date forward. This means that the initial admission assessment, including information at MDS item AB 9, was not available in the database for all residents included in the sample.

The difficulty experienced by the OIG in finding Mental Health information may be due to the timing of the study. Examination of residents' records in the facilities could have provided the needed data. However, due to the timing of the study, a number of residents selected for the sample may have either died or been discharged. The OIG did not conduct a review of closed records. Therefore, the opportunity to capture missing information gathered on the resident's admission was lost. Because the OIG study relied, in part, on information not required to be included in the MDS database for the time period studied, we suggest that the final report omit any language that refers to missing or incomplete MDS information as a negative finding of the study.

We also would point out that facilities currently are required to identify, for each resident, diagnoses that are related to the resident's current Activities of Daily Living (ADL) status, cognitive status, mood or behavior status, medical treatments, nursing monitoring or risk of death. In general, these are conditions that drive the current care plan. HCFA has not required the continued inclusion of conditions that are resolved or that no longer affect the resident's functioning or care plan.

Lastly, HCFA has recently begun work on a draft MDS version 3.0. We will consider the OIG report recommendations as we proceed with further refinements and revisions of the MDS. The development process and field-testing will be time-consuming, so any potential revision is a longer-term solution.

- **Make MDS and MSIS data available in a timely manner**

We concur with comments. HCFA agrees that it is important to fulfill requests for release of MDS and MSIS information in a timely manner.

Note that the intent of this recommendation was not clear at first. Until it was explained, we thought it meant that the OIG detected problems with timely transmission of MDS data from nursing homes to their respective State MDS databases, or with timely transmission of State Medicaid data to HCFA. We have not experienced problems with nursing home compliance with timing and frequency requirements for MDS transmission. To ensure that readers of the final report do not misunderstand this recommendation, we request that it

be re-worded. We suggest language to the effect of "More timely fulfillment of requests by HCFA, for release of MDS and MSIS information."

HCFA notes that this recommendation concerns delays experienced by the OIG in getting MDS information from HCFA for this study. At the time of the OIG's request for MDS information, HCFA was in the process of formulating requirements and specifications for request and release of MDS information. The development of these procedures included ensuring that legal matters surrounding the protection of nursing home resident's rights to privacy and confidentiality, and safeguarding the release of resident-identifiable information. Unfortunately this process is time-consuming. HCFA has finalized its procedures, and future requests for MDS information should go much more smoothly.

As for the timely availability of MSIS data, we note that the Balanced Budget Act of 1997 required all States to participate in the Medicaid Statistical Information System (MSIS) beginning January 1, 1999. One major obstacle to the successful development of a national database is that States do not always submit all their claims data through MSIS. States submit only the payment data in their state Medicaid Management Information System (MMIS) through MSIS. Historically, mental health billing data are often housed in systems outside the States' MMIS, and are therefore often missing in MSIS. Beginning in FY 1999, HCFA has emphasized to States the importance of submitting non-MMIS data through MSIS.

- **Require States to report information by age**

We concur. MSIS eligibility data as reported by the States contains the dates of birth for the individual beneficiaries. The MDS Basic Assessment Tracking Form contains the birthdate of the resident. Thus, completion of the national MSIS database will facilitate collection and validation of MSIS and MDS data.

- **Require States to report information by diagnosis**

We concur. States also report diagnosis data as part of MSIS claims. Beginning in FY 1999, HCFA has added the ability to collect more diagnosis codes on each claim. Inpatient hospital claims may now have as many as 9 diagnoses per claim and long-term care claims can contain 5 diagnoses.

The MDS identifies, for each resident, diagnoses that are related to the resident's current ADL status, cognitive status, mood or behavior status, medical treatments, nursing monitoring or risk of death. Generally, these are conditions that drive the current care plan. HCFA has not required the continued inclusion of conditions that are resolved or that no longer affect the resident's functioning or care plan.

2) **In response to the Olmstead Supreme Court Decision that requires individuals to be placed in the "most integrated and least restrictive setting appropriate," we recommend that HCFA:**

- **Facilitate the availability of (improved) MSIS and MDS data to be used to assist States in complying with HCFA's directive to identify residents and periodically review the services of all residents in Medicaid-funded institutional settings**

  We concur. Data items are currently being entered into the national MSIS database and HCFA is developing the user-friendly software to facilitate use of the data. Completion of this process is expected by late Spring 2001. After that time, HCFA will be making quarterly and annual reports public as soon as possible after they are available.

- **Encourage States to use MSIS and MDS data systems to demonstrate that the State has "a comprehensive, effective working plan for placing qualified persons with disabilities in the most integrated setting appropriate."**

  We concur. HCFA has a strong commitment to expanding home and community-based services and offering consumers the maximum amount of choice, control and flexibility in how those services are organized and delivered. Over the past few years, we have focused on expanding and promoting home and community-based services, offering support and technical assistance to States, using the flexibility of the Medicaid program.

  However, we understand that MSIS and MDS can help demonstrate, but cannot conclusively demonstrate that a State has a plan in place. We support the proactive use of existing data sources to assist States in complying with the Olmstead decision. However, we are concerned that the report's depiction of Olmstead omits important aspects of the decision, which are key to understanding why no single dataset can provide a clear cut assessment of State compliance with Olmstead.

  In the Olmstead case, the Supreme Court upheld the intention of the Americans with Disabilities Act (ADA) by recognizing that unjustified institutionalization of people with disabilities is prohibited discrimination. Title II of the ADA and its implementing regulation require public entities to administer their programs "in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (28 CFR 35.130(d)).

  The Supreme Court clearly supported the principle that institutional isolation based on disability status is discrimination under the ADA, and that a public entity has an obligation to make reasonable modifications in its programs to

offer benefits in a more integrated setting to qualified individuals with disabilities. The right of people with disabilities to receive services in the "most integrated setting" is not absolute. The reasonable-modification regulation at 28 CFR 35.130(b)(7), allow States to resist modifications that would involve "fundamental alteration" of the States' services and programs. The Court identified the following factors as relevant to the issue of fundamental alteration:

- Cost of providing services to the individual with a disability in the most integrated setting;
- Resources available to the State; and
- How the provision of services affects the ability of the State to meet the needs of others with disabilities.

Consideration should be given to the State's need to maintain a range of facilities to serve people with disabilities whose needs and preferences vary widely, and its obligation to "mete out those services equitably," administering them with an "even hand." This means considering how the immediate provision of services to individuals in the most integrated setting affects a State's ability to provide services to others with disabilities. The OIG report does not address the issue of fundamental alteration.

In addition to finding that unjustified institutionalization of people with disabilities violates the ADA, the Court found that home and community-based care should be provided to individuals with disabilities when both the State treatment professionals have determined that care in a community setting is appropriate, and affected individuals do not oppose such treatment. There is no requirement under the ADA that community-based services be imposed on people who do not desire it.

The Supreme Court's decision also suggests that individuals on waiting lists who sue to secure community-based placements or services before others on the lists will not be successful when a State can demonstrate that it is advancing its list at a reasonable pace, without regard to maintaining capacity in State institutions. States may demonstrate compliance with the ADA by showing that they have comprehensive and effective plans for placing qualified individuals with disabilities in less restrictive settings, and waiting lists that move at a reasonable pace, where such lists are maintained. The Supreme Court also suggests that States can protect themselves from piecemeal litigation by having comprehensive and effectively working plans. The OIG draft, however, implies that there is a requirement that States have comprehensive, effectively working plans. Page four of the OIG report implies that HCFA plays a role in determining State compliance. This is a misperception of the Court's ruling.

Agency Comments

To better reflect these complexities, we believe the Recommendations section of the report should be revised to reflect the following:

- The ADA is a civil rights law intended to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.

- States may choose to meet their ADA obligations to serve qualified individuals with disabilities in the most integrated settings appropriate to their needs by using their Medicaid programs, including Medicaid home and community-based services waiver programs, to make services available.

- States are responsible for enabling individuals with disabilities to remain in the community or to leave a nursing home or institution if they are able and want to do so, if the states treatment professionals determine that such placement is appropriate, and if placement can be reasonably accommodated without a fundamental alteration in the States' programs (taking into account the resources available to the State and the needs of others with mental disabilities).

APPENDIX A

Agency Comments

DEPARTMENT OF HEALTH & HUMAN SERVICES — Office of the Secretary

SEP 26 2000

The Assistant Secretary for Planning and Evaluation
Washington, D.C. 20201

TO: June Gibbs Brown
Inspector General

FROM: Margaret A. Hamburg, M.D.
Assistant Secretary for Planning and Evaluation

SUBJECT: Comments on OIG Draft Report: "Younger Nursing Facility Residents with Mental Illness: An Unidentified Population," OEI-05-99-00701

The goal of this report is to provide information about the extent to which individuals under age 65, with mental illness, reside in nursing homes. The report also addresses the question of whether existing data systems can identify such subpopulations. While the report provides some insights into the answers to these questions, our major concern is that the report may overstate the importance of the differences in the three data sets analyzed. We have a few suggestions on how the report might be improved.

1. Provide more context. Since many potential readers are not familiar with data on younger nursing home residents, please provide additional context for the highly specialized population being studied. Individuals under age 65 are a small portion of the nursing home case mix – less than 10% of nursing home residents, or about 138,000 persons according to the 1996 Medical Expenditure Panel Survey(MEPS). If one-third of these persons have some sort of mental illness, then we are searching for a relatively rare population – less than 3% of nursing home residents.

Furthermore, it is likely that non-elderly nursing home residents have multiple problems. Although the data have limitations, they suggest that not many persons end up in a nursing home solely because they have a mental illness.

The report expounds on the different numbers of younger individuals with mental illness across the different data sources. However, it is critical to note that none of the major data sources – the National Nursing Home Survey (NNHS), MEPS, and the Minimum Data Set (MDS) – were specifically designed to estimate how many persons in nursing homes have mental illness, yet all shed some light on the situation. The MDS, for example, provides two opportunities for assessors to record data on mental diagnoses. The first consists of a series of boxes which are to be checked if the resident has a specific condition, such as depression or schizophrenia. The second is a space for recording any significant diagnoses not captured by the boxes. It is important to note that the assessors are not specifically asked to rank diagnoses in terms of primary, secondary, etc. This makes the MDS difficult to compare with the Medicaid Statistical Information System (MSIS). In particular, working age adults in nursing homes who are struggling with chronic illness may also suffer from depression and require treatment, even though they would not usually be considered "mentally ill." The report should not lose sight of

the bottom line: both the MSIS and the MDS indicate that there are relatively few working age adults with mental illness in nursing homes, even though you obtained different estimates from each source.

2. Clarify your data collection methods. Please expand the description of the methodology that you employed in collecting and assembling the data for analysis. How did the OIG select the 187 cases with mental illness? Did you review 2,712 patient records in the 19 facilities, finding 385 cases with mental illness? If so, how were the 187 cases selected from the 385? Does the statement "We selected the files to review either through a random sample or a review of all residents in our study population" on page 8 refer to how the 187 cases were selected from the 385 possible cases?

3. Obtain HCFA's Comments. We strongly support your recommendations that steps be taken to improve the data systems, including the capability to match data across systems. These systems represent the first opportunity to obtain comparable data for each state, and it is important that such valuable data become available for analyses. However, ASPE does not yet have sufficient experience with these data systems to provide guidance on solving the problems that you encountered. HCFA needs to review your methodology and indicate whether the data problems that you encountered are, in fact, real problems with their data systems. If so, HCFA needs to explain how these problems are being addressed. In any event, HCFA's comments should be included in your final report.

4. Recommend MDS Improvements. The MDS provides a great deal of data on demographic characteristics, chronic illness, and functioning. However, HCFA will probably make some improvements in the MDS, based on their recent experience with the instrument. Additional information would be useful in understanding whether nursing home residents have been appropriately placed; in particular, MDS users can only guess why the person is in the nursing home instead of some other setting. There are no questions which ask for the assessor's opinion as to why the person is there. For example, in the MDS (and in other data sets), perhaps the most dramatic difference between elderly and non-elderly nursing home residents is the high proportion of the non-elderly who have seizures. One suspects that the health risk of leaving such persons without medical supervision is too great for them to remain in the community. However, this is just conjecture. Please recommend that HCFA study how the MDS might be modified to record the reason (or reasons) why the person is in the nursing home. It is difficult to determine whether people are in the most integrated and least restrictive setting unless we fully understand why nursing home care is indicated.

It would be useful to recommend that HCFA review the current Resident Assessment Protocols to determine whether the needs of residents with mental illness are being identified and served.

Thank you for the opportunity to review this report. We have also attached a draft report from a recent HCFA/ASPE study which shows how nursing home case mix varies by age group. This report may be of interest to you.

Attachment

APPENDIX A

Agency Comments