



**Rutgers** Center for  
State Health Policy

NATIONAL ACADEMY  
*for* STATE HEALTH POLICY

February  
2005

## Issue Brief

# Community Living Exchange

Funded by Centers for Medicare & Medicaid Services (CMS)

Using the Minimum Data Set (MDS) to  
Facilitate Nursing Home Transition

Susan Reinhard  
Leslie Hendrickson  
Ann Bemis

This document was prepared by Susan Reinhard and Ann Bemis, Rutgers Center for State Health Policy, and Leslie Hendrickson, Hendrickson Consulting Co.

Prepared for:



**Rutgers** Center for  
State Health Policy

Susan C. Reinhard & Marlene A. Walsh



Robert Mollica

The Community Living Exchange at Rutgers/NASHP provides technical assistance to the Real Choice Systems Change grantees funded by the Centers for Medicare & Medicaid Services.

We collaborate with multiple technical assistance partners, including ILRU, Muskie School of Public Service, National Disability Institute, Auerbach Consulting Inc., and many others around the nation.

Rutgers Center for State Health Policy  
55 Commercial Avenue, 3rd Floor  
New Brunswick, NJ 08901-1340  
Voice: 732-932-3105 - Fax: 732-932-0069  
Website: [www.cshp.rutgers.edu](http://www.cshp.rutgers.edu)

This document was developed under Grant No. P-91512/2 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. However, these contents do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the Federal government. Please include this disclaimer whenever copying or using all or any of this document in dissemination activities.

# TABLE OF CONTENTS

<b>SUMMARY.....</b>	<b>II</b>
<b>BACKGROUND.....</b>	<b>1</b>
<b>HISTORY OF THE MINIMUM DATA SET (MDS).....</b>	<b>1</b>
<b>USE OF THE MINIMUM DATA SET.....</b>	<b>2</b>
SECTION Q.....	3
WHAT MDS INFORMATION IS AVAILABLE WITHOUT A DATA USE AGREEMENT? .....	3
WHY ARE DATA USE AGREEMENTS NECESSARY? .....	5
DATA USE AGREEMENTS FOR A STATE MEDICAID AGENCY AND OTHER STATE GOVERNMENT AGENCIES .....	5
DIFFERENCES IN THE WORDING OF THE DUAS.....	6
HOW TO USE THE DATA IN NURSING HOME TRANSITION PROJECTS .....	7
EXAMPLES OF USING THE DATA IN NURSING HOME TRANSITION .....	8
SECTION S: STATE SECTION OF THE MDS .....	10
DATA USE AGREEMENTS FOR NON-STATE AGENCIES .....	10
<b>MDS VERSION 3.0.....</b>	<b>11</b>
<b>THE DATA RELIABILITY OF MDS ITEMS.....</b>	<b>11</b>
<b>THE VALIDITY OF MDS ITEMS.....</b>	<b>12</b>
<b>ACKNOWLEDGMENTS.....</b>	<b>12</b>
<b>REFERENCES .....</b>	<b>13</b>

# Using the Minimum Data Set (MDS) to Facilitate Nursing Home Transition

Susan Reinhard  
Leslie Hendrickson  
Ann Bemis

February 2005

## Summary

Consumer advocates and state leaders have been exploring ways to identify nursing home residents who want to return to their homes and communities. One effort involves the potential use of the Long Term Care Minimum Data Set (MDS), particularly Section Q, which addresses residents' discharge preference. This technical assistance document provides practical information about how state agencies can use these federal data on nursing home residents to facilitate their nursing home transition efforts. It should be read in conjunction with the February 18, 2005 guidance to State Medicaid Agency Directors on the release of MDS data (see [www.cms.hhs.gov/newfreedom](http://www.cms.hhs.gov/newfreedom).)

This Issue Brief provides information on the MDS, including web site links to federal forms and discussions of MDS-related topics. It describes two Data Use Agreements (DUA) used by state agencies and the Centers for Medicare & Medicaid Services (CMS). It recommends that agencies of the state Medicaid program use the ten-year Medicaid DUA, and discusses examples of how MDS data is used in nursing home transition projects.

## Major Points

- Consumer advocates, states, and CMS are advancing *nursing home transition programs* to help older adults and people with disabilities leave nursing homes and return to their homes and communities.
- An essential component of nursing home transition efforts is assertive identification of the nursing home residents who prefer a home- or community-based setting rather than the nursing home.
- One potential way to help identify individuals who want to transition is better use of the Long Term Care Minimum Data Set (MDS); especially section Q dealing with Discharge Potential and Overall Status of the resident.
- To obtain access to the names of individuals who express a preference to return to the community, CMS requires the completion of a Data Use Agreement (DUA), which defines the conditions under which CMS will disclose, and the user will obtain and use MDS information.
- CMS developed a customized DUA for use by state Medicaid agencies in 2002, and revised it in August 2004 to include a reference to the Americans with Disabilities Act (ADA).

## **Background**

Since 1998, CMS has been providing *nursing home transition* grants to states and their consumer advocacy partners to help residents of nursing homes relocate to their homes and communities. The first grants averaged \$175,000 and were made to four states: Colorado, Michigan, Rhode Island, and Texas. Since those early grants, CMS has continued to invest in state and local efforts to identify better strategies to support nursing home transitions. As part of President Bush's New Freedom Initiative, CMS's Real Choice System Change Initiative includes 33 grants to states and Centers for Independent Living to expand this effort. CMS has also clarified its transition policies through CMS State Medicaid Director letters and policy advice from CMS staff.

An essential component of nursing home transition efforts is assertive identification of the nursing home residents who prefer a home- or community-based setting rather than the nursing home. However, state agencies report that they experience difficulty in identifying Medicaid residents in nursing homes who wish to be discharged to a community setting. One potential way to strengthen these efforts is better use of federally mandated data about people in nursing homes. The Resident Assessment Instrument (RAI) is the statutory name of the instrument that includes the MDS, Utilization Guidelines and Resident Assessment Protocols (RAPs.) The Long Term Care Minimum Data Set (MDS) version 2.0 is a resident assessment, is part of the RAI, and is mandated by CMS. By law, all residents in Medicare and/or Medicaid-certified nursing homes must be assessed according to this prescribed instrument. Furthermore, since June 1998, CMS has mandated that nursing homes electronically transmit the MDS to CMS servers located in state agencies, for example, servers at the state survey and certification agency. The data is transmitted from the states to the federal repository at CMS.

This federally mandated MDS information, especially sections Q dealing with Discharge Potential and Overall Status of the resident and Section G Physical Functioning and Structural Problems, has been recognized as having a potential use in identifying residents qualifying for transition to home- and community-based living. The use of the MDS Section Q and other MDS data sections will contribute to the timely and accurate identification of which residents can be best helped.

## **History of the Minimum Data Set (MDS)**

The statutory authority for the MDS is found in section 1819 (f) (6) (A-B) for Medicare and 1919 (f) (6) (A-B) for Medicaid, as amended by the Omnibus Budget and Reconciliation Act of 1987 (OBRA 1987). Prior to the MDS, only aggregate quality-of-care data on nursing homes was available. With MDS, a nationally standardized person-level-of-care database is available. A state can now target quality improvement efforts within a nursing home or across nursing homes to assist particular groups of residents.

The MDS was designed by a medical center consortium under contract with CMS and was tested in about ten states beginning in the early 1990s. The goal was to assess the mental and physical functioning of each resident, and develop assessment protocols and care plans for the

resident. The tool addressed quality of care issues in nursing homes, as defined in the 1987 Nursing Home Reform Act. A revised version, Version 2.0, was published in May 1995 with approximately 350 clinical elements, and nursing homes were required to begin using it in January 1996.

Nursing homes that are Medicare-certified or Medicaid-enrolled are required to send each MDS to the state server in accordance with the federal automation regulation effective June 22, 1998. Federal regulations at 42 CFR 483.20 and 42 CFR 483.315 implement the resident assessment requirements. Nursing homes send the MDS data to the state server using the CMS RAVEN or other software programs.

MDS data is used to generate the quality improvement measures that nursing homes use in internal quality improvement and surveyors use in the survey and certification process. MDS data are also used on CMS' website "Nursing Home Compare" as a tool for selecting high quality nursing homes, and to assist states in assessing cost effectiveness and in setting long-term care nursing facility reimbursement rates.

### **Use of the Minimum Data Set**

MDS assessment forms are completed for all residents in certified nursing homes, regardless of source of payment for the individual resident. MDS assessments are conducted for all nursing home residents within 14 days of admission and at quarterly and yearly intervals, unless there is a significant change in condition. Recognizing their shorter stays, Medicare beneficiaries in a Medicare-covered stay are assessed on or before the 5th, 14th, and 30th day of their stays and every 30 days thereafter.

Citing data about MDS Coordinators within nursing homes, the General Accounting Office (GAO) found that, "Eighty-one percent of them were registered nurses, and the remainder were either licensed practical nurses, licensed vocational nurses, or social workers."<sup>1</sup> MDS information is transmitted electronically by nursing homes to their state's MDS database. MDS information from the state's server is captured in the national MDS repository at CMS.

The MDS is a part of the Resident Assessment Instrument (RAI) that originates from the nursing home reforms of the late 1980's. It is used by nursing home staff to gather information on a resident's strengths and needs in order to develop an individualized care plan. The RAI is comprised of:

- *Minimum Data Set (MDS)*: A core set of screening, clinical and functional status elements, including common definitions and coding categories for the assessment of all residents in long-term care facilities certified to participate in Medicare or Medicaid.
- *Resident Assessment Protocols (RAPs)*: Structured, problem-oriented frameworks for organizing MDS information, and examining additional clinically relevant information

---

<sup>1</sup> GAO (2002), p. 7.

about an individual. RAPs help identify social, medical and psychological problems and form the basis for individualized care planning. More than 18 different RAPs have been developed since the MDS was introduced.

- *Utilization Guidelines:* Instructions concerning when and how to use the RAI.<sup>2</sup>

One study found that assessment and care-planning quality improved with the initial introduction of the MDS, and in 2001, an Office of the Inspector General study found that care plans were generally consistent with the MDS. Although the MDS has been computerized since 1998, there has been relatively little use of MDS summaries as a means of enhancing clinical communication or transferring resident information at the time of hospitalization.<sup>3</sup>

The CMS website for information about the MDS is at:

<http://www.cms.hhs.gov/medicaid/mds20/>

## Section Q

The MDS includes several sections. Section Q questions are worded as shown below:

<b>Q1a: Discharge Potential and Overall Status</b> Resident Expresses/Indicates Preference to Return to the Community
<b>Q1b: Discharge Potential and Overall Status</b> Resident Has a Support Person Who is Positive Towards Discharge
<b>Q1c: Discharge Potential and Overall Status</b> Stay Projected to be a Short Duration - discharge projected within 90 days
<b>Q2: Discharge Potential and Overall Status - Overall Change In Care Needs</b> Residents overall self sufficiency has changed significantly as compared to status of 90 days ago

## What MDS Information is Available without a Data Use Agreement?

State Survey and Certification staffs are federally required to calculate 24 quality indicators for each nursing home surveyed. State survey staffs use personally identifiable MDS answers to create the Quality Indicator Resident Report that includes a resident roster with checks for each quality indicator that is present for each resident. During the survey, staff will

---

<sup>2</sup> CMS (2002, December), p. 1-4.

<sup>3</sup> Mor (2004).

select residents to interview based on their MDS answers. This survey work occurs without a DUA. However, state survey staffs are not permitted to share any MDS answers with other state agencies, researchers, or any other persons without a DUA.

CMS has made six reports available on its website:

- *Nursing Home Quality Indicator Reports*: Present data on 24 indicators of quality of care (32 with subcategories). These data are also presented at state and national levels.
- *Active Resident Information Reports*: Contains data for residents currently in nursing homes presented at state and national levels.
- *Assessment counts by Reason for Assessment*
- *Resource Utilization Groups (RUGS)*
- *RUGS by Reason for Assessment*
- *Frequency Reports*: Give a picture of the characteristics of the nursing home population in each state and nationally through presentation of data on frequency of responses to specific MDS items.

The report relevant to this discussion, the Active Resident Information Report, summarizes information collected on residents currently in nursing homes. Items contained in this report include those from Section Q of the MDS, which concerns information on residents' potential discharge status. To view the Active Resident Information Report, go to:

<http://www.cms.hhs.gov/states/mdsreports/default.asp>

Scroll to the bottom of the page to the “**Select report type:**” drop-down menu and select the option “**MDS Active Resident Information Report.**”

Click “**Submit**”

Scroll to the bottom of the following screen to the “**Select report date:**” drop-down menu and enter the data period.

To view a state-by-state report for each MDS item, click on the section letter and question number in the “**Variables**” column.

Currently, the Active Resident Information Report with section Q data is displayed at the state and national levels. This aggregate level of information is not helpful to state Medicaid and non-profit agencies seeking to identify residents who may benefit from community-living counseling. Therefore, some community organizations have requested that the report be adapted to provide information on a nursing facility or county-level. Obtaining information at this level of detail would enable state agencies to more efficiently direct their resources to specific locations and facilities that have a larger or a more targeted population of residents expressing an interest in returning to community-living situations (Q1(a)).

At this time, CMS is providing MDS information on a county-level to enable improved targeting processes. It is less likely that this data will be available on a facility level.

## **Why Are Data Use Agreements Necessary?**

The DUA protects the confidentiality of resident data. MDS information is protected under the Privacy Act of 1974 and permitted disclosures of it are listed in the System of Records. The Privacy Act of 1974 and the System of Records are CMS's legal authorization to release the data, and these legal requirements protect the confidentiality of individually identifiable data.

For additional detail on the Privacy Act see:

[http://www.usdoj.gov/foia/04\\_7\\_1.html](http://www.usdoj.gov/foia/04_7_1.html).

Also, see the 2003 Privacy Act Issuances Compilation at the GPO access site:

[http://www.access.gpo.gov/su\\_docs/aces/PrivacyAct.shtml](http://www.access.gpo.gov/su_docs/aces/PrivacyAct.shtml).

Section # 09-70-1517 covers the CMS use of the MDS.

The System of Records #09-70-1517 establishes that information in the MDS may be routinely disclosed:

“2. To another Federal or state agency, agency of a state government, an agency established by state law, or its fiscal agent to,...c. Assist Federal/state Medicaid programs within the state.”

The Data Use Agreement defines the conditions under which CMS will disclose, and the user will obtain, MDS information. Different DUAs are required depending upon the type of requestor asking for the data. See:

<http://www.cms.hhs.gov/privacyact/requests/>

## **Data Use Agreements for a State Medicaid Agency and Other State Government Agencies**

Over the years, CMS has developed customized DUAs for different types of requesters. CMS has the authority to release MDS data to state Medicaid agencies under System of Records #0-70-1517 2(c). In late 2002, CMS developed a DUA for use by state Medicaid agencies and revised it in August 2004 to include a reference to the Americans with Disabilities Act (ADA). This DUA is titled:

### **Medicaid Agency Data Use Agreement Agreement for use of Centers for Medicare & Medicaid Services (CMS) Data Containing Individual-Specific Information**

More than a dozen states now use Medicaid DUAs. The Medicaid DUA is the appropriate one to use for agencies wishing to obtain MDS data for use in nursing home transition efforts. This agreement can be accessed at

[www.cms.hhs.gov/privacyact/requests](http://www.cms.hhs.gov/privacyact/requests)

In the section titled “**Types of Requestors**,” click on “**State Medicaid Agency LTCMDS**.”

Click on “**10-Year Medicaid Data Use Agreement**.”

The submission process entails filling out the DUA and submitting it to the CMS regional office where MDS coordination activities are based. When the DUA is implemented, the data are obtained from the server at the state and not from CMS. Previous to the data being released, the state must have the ability to track releases at the beneficiary level to fulfill the Health Insurance Portability and Accountability Act (HIPPA) requirements. States must have a process to generate an audit trail of the names of persons whose MDS information is released. States can also ask CMS to generate the audit trail on the national server.

Outside of survey and certification uses and other state Medicaid uses, a *standard* DUA can be used by state agencies to obtain access to the MDS data. Permission for access to the specific data elements can be formally requested from CMS through submission of a standard DUA.

This DUA is titled:

**Data Use Agreement  
Agreement for Use of Centers for Medicare & Medicaid Services (CMS)  
Data Containing Individual-Specific Information**

This form and instructions for completing this DUA can be found at:

<http://www.cms.hhs.gov/privacyact/requests/government.asp>.

At this site, select “**Data Use Agreement.**” Again, the process is to fill out the DUA and submit it to the staff person at the CMS regional office who does MDS coordination activities. See the CMS request policies at:

[www.cms.hhs.gov/privacyact/requests](http://www.cms.hhs.gov/privacyact/requests).

Data are obtained from the MDS server at the state or through CMS’ National Systems Group in Baltimore. As with data obtained by a state Medicaid agency, after the data request is granted, an audit tape is sent to Baltimore identifying the residents that had their records accessed.

### **Differences in the Wording of the DUAs**

There are substantial differences in the wording of the instructions and the two state federal government DUAs.

Item #6 of the non-Medicaid DUA is open and allows the requestor to propose a project that will improve the quality of care and quality of life of nursing home residents. The Medicaid DUA contains a standard paragraph that substitutes for the extensive research protocol descriptions required in the DUA for non-state Medicaid agencies. The non-Medicaid wording requires that the data be used only for the purposes listed in the research protocol, whereas, the Medicaid DUA is the disclosure of MDS data for purposes of administering the Medicaid program.

Item #6 in the Medicaid DUA reads:

6. The User represents, and in furnishing the Medicare LTC/MDS, CMS relies upon such representation, that this file(s) will be used solely for the purpose(s) outlined below.

To facilitate the administration of a Federal health program for the purposes of determining participation requirements, evaluating and/or assessing cost effectiveness, and/or the quality of health care services provided, and/or for setting long term care Nursing Facility reimbursement rates in the State that are directly related to the administration of the State Medicaid Program. To facilitate State compliance with the requirements of the Americans with Disabilities Act.

The last sentence is important. It is not in other versions of the DUA and it authorizes the use of the MDS data in transition programs.

Item #8 of the Medicaid DUA extends the duration of the approval to ten years, versus the five-year limit found in the standard DUA. In the standard DUA, the wording of item #8 requires the return or destruction of the data as soon as the research purposes identified in item #6 are accomplished.

Items #12 through #19 are different in the two DUAs and reflect the differences in a DUA authorizing a limited use of data for a listed research purpose versus the discretionary use of data for purposes of assisting the administration of the state's Medicaid program.

## **How to Use the Data in Nursing Home Transition Projects**

The language in federal law says that the MDS can be routinely disclosed to the following:

2. To another Federal or state agency, agency of a state government, an agency established by state law, or its designated agent...

Medicaid agencies have authority to share the data with lawfully designated agents under contract with the Medicaid agency for the purpose of administering a part of the state's Medicaid program. For example, in the Medicaid DUA the "Custodian" of the data files can be a contractor of a Medicaid agency. There is no authority to share the data with non-profit agencies or private providers that are not under contract with the Medicaid agency.

CMS has established policies and procedures consistent with the Privacy Act of 1974 regarding the privacy rights of individuals enrolled in Medicaid. These rules require that agency staff and contractors use individual data in a confidential manner that respects the privacy rights of each individual. As authorized under federal law and procedure, State Medicaid agency rules permit the use of personally identifiable information in the administration of the Medicaid program. Projected uses of the MDS information, as discussed below, are compatible with these customary practices.

The Medicaid Agency and/or its designated agent/custodian can select the information to identify those individuals eligible for nursing home transition services, once a Medicaid DUA is

executed and MDS data is obtained from staff that maintains the state's MDS server. Advocacy organizations have argued that everyone who wants to leave a nursing home should be approached, and that the resident should be the primary focus rather than their resources or social supports. Given the agency's limited budget and staff levels, some states may decide to maximize the persons helped by first focusing on persons with the desire and resources required to make a successful transition to home- or community-based residence. Those who take this approach will integrate information on projected length of stay (Q1(c)), change in care needs (Q2), and existing family support systems (Q1(b)), with the expressed desire for discharge (Q1(a)) to initially target the population of individuals that may be able to transition quickly. This targeting may increase the number of persons served by the project and permit more resources to be dedicated to transitioning those who need substantial help in relocating.

Indicators of the resident's social support are found in Sections R and Q. Section R has one question. It asks if the resident, family, or significant other participated in the assessment. R1 (a), (b) and (c) can be used in conjunction with Q1(b) to find out if there are persons who may be contacted about the care provided to the resident. The MDS provides no information about who that person(s) is, only that there is a person or family member involved. In addition, Section G can be used to obtain information on physical functioning and activities of daily living, and persons with cognitive conditions could be identified using sections B and C.

The choice of how to identify persons depends on the intended policy that is being implemented. On the one hand, some nursing home transition programs view residents who have shorter-term stays in nursing facilities as better candidates for transition to community living, because their support system and overall health status are usually stronger during the early stages of institutionalization. Depending on the state's shelter allowance, and the resident's financial and housing conditions, these residents may still have a house or apartment. Consequently, these residents might receive more initial help or follow-up assessment.

On the other hand, some persons enter a nursing home as Medicare and/or private pay residents. After these funds are depleted, these same individuals may ultimately spend-down to Medicaid income levels. However, these long-term individuals may still have the potential to benefit from a discharge plan that includes community residence. Moreover, even helping someone who would be in for a shorter Medicaid stay can be cost effective, if the length of the stay is reduced.

The website of the **Iowa** Foundation for Medical Care has a page on containing MDS data by state by county on the age and Medicare status of persons who answered yes to Q1(a): <http://www.qtso.com/mdsdownload.html>.

### **Examples of Using the Data in Nursing Home Transition**

Medicaid agencies and/or their designated agents can use any combination of MDS answers it thinks useful to estimate the number of persons to contact. Agencies can then

interview the persons and review their choice of care and current eligibility for Medicaid home and community-based services.

For example, in calendar year 2004, the **New Jersey** nursing home transition program, known as Community Choice Counseling, helped 258 persons. How do you find 258 persons out of the 29,000 Medicaid persons in New Jersey's nursing homes?

In 2004, New Jersey staff looked at the 15% of their nursing home residents that answered a Yes to Q1(a), "Resident expresses/indicates preference to return to the community." Then staff used the answers to filter out those persons who were in for a short-term Medicare stay, persons whose physical condition worsened recently, and persons who said they had no social supports. These filters took out 9% of the 15%. The remaining 6% of the residents comprised 800 persons and the transition staff thereby identified potentially eligible persons to meet with.

Project Out, a nursing home transition project in **Wyoming** initiated in October 2002, used Section Q data. It used question Q1(a), "Resident expresses/indicates preference to return to the community." When used in 2003, its MDS Active Resident Information Report indicated that 22 % of the nursing home residents in Wyoming, or 532 individuals, wished to return to the community. For a description of this project, see:

<http://www.hcbs.org/files/30/1459/ProjectOutl.doc>.

In late 2004, the **Louisiana** Governor's Office of Disability Affairs used its state's Section Q data in discussing nursing home transition efforts. See:

<http://www.gov.state.la.us/disabilityaffairs/dsss/DSSS%20Minutes.asp>

As part of its One to One transition program begun in 1999, **Vermont** identified candidates for nursing home transition through two methods. First, coalitions identified transition candidates through the Medicaid assessment process for admission to a nursing home. Second, the state used MDS data covering desire to live in the community, bowel and bladder continence, cognition, and their Medicare Resource Utilization Group (RUG) score. The Vermont experience revealed that the list decreased in value over time. The longer the lag between when the MDS questions were answered and when transition workers visited the nursing home, the less valuable the list became. This informative experience could indicate that a state should use a timely system that runs incoming MDS submissions from the homes through a filter, so that persons who answered questions in specific ways would be flagged and their answers would automatically be sent to field staff making visits to the nursing homes. See:

<http://aspe.hhs.gov/daltcp/reports/VTtrans.htm>.

Another example is the use of the MDS data in staff training and planning for work with persons with disabilities who are under the age of 65. The MDS data could be used to identify these persons under-65 by using Section G questions on physical functioning. The provision of services to a disabled person under 65 requires different staff training and planning. For example, finding affordable housing with accommodations for the disability is often an issue. The program requires staff with a good knowledge of the housing market. The eligibility of these people under-65 for housing and community residence-based services could be reviewed by these staff.

MDS data might be useful here to see how the program's services and budget can be better matched to the needs of the persons.

## **Section S: State Section of the MDS**

Section S is an optional part of the MDS, where states can add unique questions to resident assessments to collect data for operations, research or evaluations. For example, Section S information can be added to determine how discharge planning and transition work could be improved.

It has been proposed that in Section S, a state might be able to provide a place where the resident could approve the release of his or her name to a community-living counseling agency. However, the same federally mandated privacy protection laws that apply to the MDS also apply to Section S data, and the same procedures must be followed for its use.

## **Data Use Agreements for Non-State Agencies**

The Data Use Agreement defines the conditions under which CMS will disclose, and the user will obtain and use MDS information. All requests for MDS information must be submitted to the CMS regional office for approval of the proposed data use. Different data request procedures are required depending upon the type of organization asking for the data. To determine the criteria for your organization, go to:

<http://www.cms.hhs.gov/privacyact/requests/>

For assistance in composing requests for and/or using CMS data, you can contact:

- CMS's **Data Use and Policy Hotline** at: 410-786-3690.
- **The Research Data Assistance Center (ResDAC)** is a CMS contractor that provides free assistance to academic, government and non-profit researchers interested in using Medicare and/or Medicaid data for their research.

You can contact ResDAC in several ways:

- Using a web-based application called the Request Response and Transmission System (RTTS) to submit a written request (<https://resdac.oit.umn.edu/>)
- Research Data Assistance Center (ResDAC)

University of Minnesota  
School of Public Health  
Division of Health Services Research & Policy  
420 Delaware Street SE  
D355 Mayo Memorial Building (MMC 97)  
Minneapolis, MN 55455  
E-Mail: [resdac@umn.edu](mailto:resdac@umn.edu)  
Phone: 1-888-973-7322  
Fax: 612-378-4866  
URL: [www.resdac.umn.edu](http://www.resdac.umn.edu)

Researchers are required to send a DUA to ResDAC for review. When filling out this DUA, a requestor needs to include detailed, specific information on the intended use of the MDS information. Items to incorporate in the DUA are the purpose (i.e., number and type of studies conducted), number of reports to be run, identification of risks, project description, monitoring and quality maintenance procedures, and the use of MDS data in the needs assessments.

The research requestor pays a fee and obtains data directly from CMS in Baltimore. Once the request is reviewed and approved by the Survey and Certification component of CMS and/or the CMS Privacy Board, it is sent to the CMS Office of Information Services. It usually takes approximately six weeks for the data to be delivered to the requestor.

A collection of MDS-related forms can be found at:

<http://www.cms.hhs.gov/quality/mds20/>

### **MDS Version 3.0**

A new version of the MDS is currently under development. Information regarding the status of this project can be found at:

<http://www.cms.hhs.gov/quality/mds30/>

### **The Data Reliability of MDS Items**

The reliability of a measure is its consistency in measuring the characteristics it is designed to measure. Nursing home differences in data collection methods have the potential to influence the integrity of MDS information. Another influence on data reliability may arise from an environment where reimbursement systems pay facilities more for serving patients with more complex clinical needs. For example, it has been suggested that homes have an incentive to “upcode” or maximize patients’ frailties. Alternatively, the use of MDS data for publicly accessible performance measurement, such as in the nursing home quality reports, may create opposite tendencies. To date there has been no empirical testing of the effect on data from such factors. One Office of the Inspector General (OIG) report found that “upcoding” was no more common than “downcoding,” and that any differences were likely due to error rather than intent.<sup>4</sup>

Some state agencies have been uncertain about the reliability of the MDS. For example, Wisconsin’s ADA Title II Advisory Committee in 2002 recommended conducting a “scientifically significant sample” of nursing home residents to learn how many are interested in living somewhere other than the nursing home. The workgroup believed that a face-to-face interview and specialized interview questions would identify persons who could make a successful transition to the community.

The MDS has been repeatedly tested for inter-rater reliability among nurse assessors in nursing homes.<sup>5</sup> Results of these tests showed high average levels of reliability. A modified

---

<sup>4</sup> Mor (2004).

<sup>5</sup> Frakt, et al (2004).

version of the MDS was designed and re-tested in 1995 and was found to have improved reliability over the first version of MDS. The largest field reliability trial of the MDS yet was conducted as part of a multi-state study of the validity of summary indicators of facility quality based on the MDS. Results revealed that over 85% of MDS data elements exhibit adequate inter-rater reliability and that those below the threshold were still very high levels of agreement.<sup>6</sup>

In January 2004, CMS implemented its Data Assessment and Verification Project (DAVE) nationally. The primary objective of the DAVE project is to assess the accuracy and reliability of assessment data that nursing homes submit. These oversight procedures, combined with ongoing CMS question and answer programs and manuals, and the many MDS training programs sponsored by providers, will result in improved reliability. The DAVE website is:

[www.cms.hhs.gov/providers/psc/dave/homepage.asp](http://www.cms.hhs.gov/providers/psc/dave/homepage.asp).

### **The Validity of MDS Items**

The validity of a measure is the degree to which an instrument actually measures what it is intended to measure. The validity of the MDS has been examined by studies where established research or clinical tools were compared with either a specially conducted MDS assessment or with an existing MDS assessment. The results of the pre-national activities showed that the most common discrepancies between the medical record and the reported MDS answers were found in five major MDS areas:

- **Section G** — Physical Functioning and Structural Problems
- **Section I** — Disease Diagnoses
- **Section J** — Health Conditions
- **Section O** — Medications
- **Section P** — Special Treatments and Procedures

For a national discussion of MDS discrepancies see: General Accountability Office (GAO) February 2002 report titled, “Nursing Homes: Federal Efforts to Monitor Resident Assessment Data Should Complement State Activities.” The GAO website for this report is:

<http://www.gao.gov/new.items/d02279.pdf>

### **Acknowledgments**

We wish to express gratitude to the following people for their contributions to this document: Tina Miller, Joan Simmons and Melissa Hulbert of the Centers for Medicare & Medicaid Services; staff interviewed in the New Jersey Department of Health and Senior Services; and all of the Nursing Facility Transition grantees awarded under the Real Choice Systems Change initiative.

---

<sup>6</sup> Mor (2004).

## References

Berg, Katherine, Ph.D., and Vincent Mor, Ph.D., John Morris, Ph.D., Katharine M. Murphy, Ph.D., R.N., Terry Moore, M.P.H., R.N., and Yael Harris, "Identification and Evaluation of Existing Nursing Homes Quality Indicators" M.H.S. HEALTH CARE FINANCING REVIEW/Summer 2002/Volume 23, Number 4 pp. 19-36

Centers for Medicare & Medicaid Services (CMS). (2002, December). MDS 2.0 Manuals and Forms. Chapter 1. Retrieved on February 9, 2005 from <http://www.cms.hhs.gov/quality/mds20/>

Community Living Exchange Collaborative. (2004, August). Audio-conference transcript, Exploring the Potential Use of MDS Section Q1. Accessed on February 9, 2005 from [www.hcbs.org](http://www.hcbs.org)

Centers for Medicare & Medicaid Services (CMS). Various web sites included in paper. Retrieved February 9, 2004 from <http://www.cms.hhs.gov>

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter [Release of Long Term Care Minimum Data Set \(LTC/MDS\) Data to State Medicaid Agencies, Section 1915 Waiver Programs, and "Real Choice Systems Change Grant" Programs in Order to Assist States' Title II, Americans with Disabilities Act \(ADA\) Compliance Activities](#) 02/18/05 on [www.cms.hhs.gov/newfreedom](http://www.cms.hhs.gov/newfreedom).

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter 04-005 [Money Follows the Person \(MFP\)](#) 08/17/04

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter 03-008 [Additional examples and clarification on the principle of "Money Follows the Person"](#) 09/17/03

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter 03-006. [The Transition of Individuals from Institutional to Community Settings Through Medicaid Coverage of Medical Equipment \(ME\) Costs](#) 07/14/03

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter 02-012 [Promising State Practices](#) 8/13/02

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter 02-009 [Independence Plus](#) 5/9/02

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter 02-008 [1915\(c\) Transitioning Waivers](#) 5/9/02

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter 01-007 [Olmstead Update Number 5 \(New Tools for States\)](#) 1/10/01

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter 01-006 Olmstead Update Number 4 <http://www.cms.hhs.gov/states/letters/smd11001.pdf> 1/10/01

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter Olmstead Update Number 2 (Issues and Answers) <http://www.cms.hhs.gov/states/letters/smd72500.asp> 7/25/00

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter Olmstead Update Number 3 (HCFA Update) <http://www.cms.hhs.gov/states/letters/smd725a0.asp> 7/25/00

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter Nursing Home Transition Grant (2000) <http://www.cms.hhs.gov/states/letters/smd53100.asp> 5/31/00

Centers for Medicare & Medicaid Services (CMS). State Medicaid Director Letter Nursing Home Transition Grant funding to 8 States over the Past 2 Years <http://www.cms.hhs.gov/states/letters/smd04280.asp> 4/28/00

Code of Federal Regulations at [42 CFR 483.20](#) and [42 CFR 483.315](#) present Federal regulations implementing resident assessment.

Centers for Medicare & Medicaid Services (CMS). State MDS websites at: <http://www.cms.hhs.gov/medicaid/mds20/mdssites.asp>

Eiken, S, Hatzmann, M. & Ascitutto, A.J. (2003). One-to-One: Vermont's Nursing Home Transition Program. Prepared under contract #HHS-100-97-0019 between the U.S. Department of Health and Human Services (HHS), Office of Disability, Aging and Long-Term Care Policy (DALTCP) and The MEDSTAT Group.

Federal Register. Vol. 62, No. 246, 42 CFR Part 483, December 23, 1997. Medicare and Medicaid; Resident Assessment in Long Term Care Facilities; Final Rule (Implementation of MDS Automation). Found at: <http://www.health.state.ok.us/PROGRAM/qies/mds/dec2397.pdf>.

Frakt, A., Wang, M., & Pizer, S. Validating MDS data from VA nursing home care units: Comparing VA and community quality measures. Health Care Financing & Economics, VA Boston Health Care System Research & Development. October 13, 2004. See <http://dcc2.bumc.bu.edu/chqoer/HCFE/mysite3/DB%202004-03.pdf>

General Accountability Office (GAO). (2002, February). Nursing Homes: Federal Efforts to Monitor Resident Assessment Data Should Complement State Activities.” Found at: <http://www.gao.gov/new.items/d02279.pdf>.

Mor, V. (2004). A comprehensive clinical assessment tool to inform policy and practice: Applications of the minimum data set. *Medical Care*, 42(4), III-50 – III-59.

State of Wisconsin, Wisconsin Council on Long Term Care. (2002, January). ADA Title II Advisory Committee. Wisconsin's ADA Title II Plan Phase 1. Found at: <http://www.wcltc.state.wi.us/PDF/ADAPlan1-02.pdf>.