Discussion Paper

Community Living Exchange

Money Follows the Person: States' Progress in Using the Minimum Data Set (MDS) to Facilitate Nursing Home Transition

Susan C. Reinhard
Leslie Hendrickson

Susan C. Reinhard & Marlene A. Walsh

Robert Mollica

TABLE OF CONTENTS

Discussion Paper:

Money Follows the Person: States' Progress in Using the Minimum Data Set (MDS) to Facilitate Nursing Home Transition

Susan C. Reinhard
Leslie Hendrickson

June 2006

Summary

For more than a decade, state and federal officials have joined consumer advocates in advancing the goal of helping nursing facility residents return to their homes and communities. The first step in this process is identifying people who want to leave the nursing facility.[1] The need for data to support this identification varies by state. A few states, such as Oregon, Washington, and New Jersey, routinely approach all nursing facility residents early in the admission process and throughout their nursing facility stay.[2,3,4] This routine and ongoing interaction with all nursing home residents, regardless of payer source, may obviate the need for a data source to identify those residents who seek help in relocating back to the community. It also supports a robust "money follows the person" (MFP) policy that incorporates both nursing facility diversion and transition strategies.[5] Other states that have not yet established this infrastructure for routine options-counseling and nursing home transition are seeking systematic ways to identify people in nursing facilities who have expressed a desire to leave and might benefit from outside help to do so.

One potential method to accomplish this objective is using the Long-Term Care Minimum Data Set (LTC/MDS, or more commonly known as the MDS), especially Section Q, which addresses a person's discharge preference. The Rutgers/NASHP Community Living Exchange has provided practical information on how state agencies can obtain and use the MDS through Data Use Agreements (DUAs) with the Centers for

---

[1] Nursing facility staff support some discharge planning, but states and consumer advocacy groups purport that the incentive to keep nursing facility occupancy as high as possible is a disincentive for assertive discharge planning by the facility itself.

[2] Reinhard & Petlick (2005).

[3] Mollica (2005).

[4] Justice & Heestand (2003).

[5] A strong nursing home diversion strategy helps people <u>avoid</u> unwanted nursing home placement.

Medicare & Medicaid Services (CMS).[6] This technical assistance document explores the progress states have made in: using the MDS to facilitate nursing facility transition; identifying barriers that remain; and, suggesting recommendations for changes to the MDS to make it more useful for nursing home transition efforts. We examine three uses of the MDS by nursing facility transition programs: the distribution of MDS Q1a answers as an advocacy tool; the review of MDS records by transition workers while working in a nursing home; and, its use in generating a list of names as possible referral for transition work.

This report is based on Internet searches and communication with 33 CMS nursing home transition grantees, states that have seven or more DUAs, and selected researchers. It is part of the *Money Follows the Person Toolbox* designed to help states develop and implement effective programs, including the demonstration projects called for in the 2006 Deficit Reduction Act.[7]

Major Points

- Different state "money follows the person" strategies affect the kind of data that states and their partners need to help them identify people in nursing homes who want to return to their communities.

- One potential way to identify people in nursing homes who wish to leave is to make better use of the Long-Term Care Minimum Data Set (MDS), especially Section Q, which addresses the person's discharge preferences.

- Access to the MDS database is obtained by completing a Data Use Agreement (DUA) with CMS.

- Once the DUA is established, the next challenge is accessing the MDS data in a timely way, making useful data queries, and using the findings.

- Nursing facility transition projects do not use MDS data for six reasons, including the availability of referrals from other sources, the size and technological capabilities of the projects, and staff members' reservations about the validity and reliability of MDS sections.

- Recommended changes to the MDS instrument and process can improve the usefulness of these data for those who want to counsel people in nursing homes about the full range of their long-term care choices. For example, moving up the discussion of discharge preferences to the beginning of the MDS would provide more visibility and emphasis for both the consumer and nursing home staff.

---

[6] Reinhard, Hendrickson, & Bemis (2005).
[7] The *Money Follows the Person Toolbox* is being developed by the Rutgers/NASHP technical assistance team in collaboration with the 2003 Money Follows the Person grantees that are funded by the Centers for Medicare & Medicaid Services. For more information, contact Marlene Walsh at mwalsh@ifh.rutgers.edu.

Background

State and federal officials have joined consumer advocates to advance the goal of helping nursing facility residents return to their homes and communities. Some states include this help as a routine part of their outreach and case management work with all nursing home residents. Washington, for example, assigns state-employed case managers to nursing homes so that they can talk to every person admitted to that home within seven days, not just people on Medicaid.[8] As a state that serves 63% of its clients outside of institutions, this state's "money follows the person" strategy is to serve consumers who need long-term supportive services in the setting of their choice. It is not limited to offering choices to people on Medicaid who are already residing in nursing homes.

> **Different state "money follows the person" strategies affect the kind of data that states need to help them identify people in nursing homes who want to return to their communities.**

Texas, which has significant waiting lists for home and community-based services like many other states, has developed a different "money follows the person" strategy. As an important step toward a more balanced long-term care system that supports consumer choice, this state focuses attention on moving people out of nursing homes by prioritizing them for Medicaid home and community-based services. As clients relocate from nursing facilities to community care, funds are transferred from the state's nursing facility budget to its community care budget, to cover the cost of the shift in services.[9]

These different state "money follows the person" strategies affect the kind of data that states need to help them identify people in nursing homes who want to return to their communities. Where there is routine, early and ongoing interaction with all nursing home residents, there may be less of a need for systematic analysis of the MDS or other data sources. Where this infrastructure is not in place, it may be helpful to use the MDS to reach out to those who may want more information about how to achieve their preference for a living situation outside of the nursing home.

An earlier technical assistance document provided examples of how the MDS can be used for nursing home transition and how states can obtain a Data Use Agreement (DUA) to make this possible.[10] A 2005 letter to State Medicaid Directors' provided federal guidance on disclosure of MDS data to help states comply with the integrated care setting and reasonable accommodation requirements of the American Disabilities Act.[11] In monitoring states' application and implementation of DUAs for the MDS, the authors found an accelerated pace in state applications for DUAs, but difficulties in obtaining the actual data and using it for the purposes of nursing home transition.

---

[8] Mollica (2005).
[9] Gold (2006).
[10] Reinhard, Hendrickson, & Bemis (2005).
[11] Hamilton & Arden (2005).

The Long-Term Care Minimum Data Set (MDS)

The basic assessment form in the MDS, formally called the Resident Assessment Instrument or RAI, is a nine-page questionnaire containing approximately 120 items. There are about 530 response options spread across 24 sections, or "domains" of the form that may be filled-in for a specific nursing home resident. The data from these response options form the minimum data set or MDS. The MDS forms and manuals can be found and downloaded at the CMS website.[12] MDS items collect data on the nursing home resident's physical and cognitive status, medical and dental conditions, nutritional status, behavioral and emotional status, and preferences. The MDS is significant because it is the only resident-level data required from all nursing homes and it provides standardized national data.

Introduced in 1991 and annually improved, statutory authority for the use of the MDS is found in sections 1819(f)(6)(A-B) and 1919(f)(6)(A-B) of the Social Security Act, and it is implemented in federal regulations at 42 CFR 483.20(b) and (c). For example, nursing home staff is required to use the MDS to make an initial assessment, periodic assessments after the initial data collection, and when there has been a change in the condition of the nursing home resident.

CMS collects about ten million MDS records annually[13] on the approximately three million persons who use nursing homes each year.[14] This is a large amount of information, which should be used to benefit consumers.

The MDS has become an anchor for research on older populations. Its applicability has been extended through the development of MDS-related instruments to collect data on persons in home care and residential settings. Inter-Resident Assessment Instrument (RAI) researchers have developed eleven MDS-like instruments to collect data on persons in different care settings.[15] States such as Maine have also developed their own MDS-related instruments. The power of related instruments is due to the overlap with the MDS. An instrument could use 80% of the MDS items and the other 20% of the information gathered could be specific to the care setting. The interRAI's MDS Home Care (MDS-HC) instrument has a 47% overlap with the MDS. The overlap permits a meaningful comparison of the persons using the different care settings. The focus on nursing home transition has intensified interest in collecting data across settings for individuals' care planning, as well as statewide policy and program development.

Who Has Data Use Agreements (DUA) to Use the MDS?

Access to this immense database is obtained by completing a Data Use Agreement (*see **Appendix A***). The CMS website contains extensive information on the types of DUAs that CMS supports, and the procedures and forms for submitting a

---

[12] Centers for Medicare & Medicaid Services (2006).
[13] Mor (2004).
[14] Tucker & Decker (2004).
[15] The InterRAI website at http://www.interrai.org/section/view/ contains descriptions of 11 MDS-related instruments.

DUA.[16] As of March 2006, there were 262 active DUAs for using MDS data.[17] The "requesting organization" of these 262 DUAs falls into four main categories: states; universities; federal government use; and, health care organizations and private and non-profit research organizations.

States are significant requestors of MDS data, having 120 (46%) of the 262 DUAs. All but five state executive departments, Delaware, South Carolina, South Dakota, North Dakota and Missouri, have requested and have active DUAs.

Of the 120 DUAs requested by states, about 40 have a "custodian organization" that is different from the state "requesting organization." In 15 of the 40 instances, Myers and Stauffer, a private consulting firm that does nursing facility rate setting, is listed as the custodian organization. This reflects a major use of MDS in nursing home reimbursement. Approximately 28 states use the MDS to set case-mix reimbursement for the staffing component of the Medicaid payments to the state's nursing homes.[18] Medicare uses the MDS to assign residents to payment categories called Resource Utilization Groups (RUGs) and sets a per diem payment for each day a resident is in a particular RUG category. In the last ten years, state Medicaid reimbursement has also shifted to using the MDS to help set rates for Medicaid payments to nursing homes.

Universities and medical schools are significant users of the MDS, having about 72 (27%) of the 262 active DUAs. *Appendix A* summarizes the largest university users' and researchers' major use of the MDS. About 10% of all MDS DUAs are used by federal organizations responsible for monitoring and oversight of Medicare and Medicaid activities. The federal government's largest users are the Office of the Inspector General with 12 DUAs, the Department of Justice with six, and the General Accounting Office with five. The Attorney General's offices of both New York and California also have DUAs.

The remaining 15% of the DUAs are spread over national and state research organizations, quality improvement organizations, and health care providers and non-profits.

---

[16] Reinhard, Hendrickson & Bemis (2005).

[17] A list of active DUAs related to the Minimum Data Set was obtained from CMS. For purposes of this report, a state DUA was defined as any DUA where the word "state" was used to identity a state as either the requesting organization or the custodian organization. This definition was chosen to emphasize executive departments and excludes public universities and colleges.

[18] Washington State Department of Health and Social Services, (October 2003). These states are CO, CT, GA, ID, IO, IN, KS, KY, NC, LA, MA, MN, MS, MO, NE, NV, NH, NC, ND, OH, PA, SD, UT, VT, VA, WA, and WV. In Missouri, the University of Missouri has a DUA in which a rate setting vendor is the custodian. In North Dakota, the Medicaid agency requires nursing homes to submit their MDSs to the agency directly and to the federal server in the Health Department.

What State Agencies Do With Minimum Data Set Information

To explore states' use of the MDS to facilitate nursing home transition, we examined the DUAs from seven states that have five or more DUAs, as well as states that had obtained a CMS nursing home transition grant. Our focus was on the barriers to accessing the MDS once a DUA is established and the usefulness of the data in helping consumers transfer.

States that have the most DUAs include: Kansas (5), Maryland (5), New Jersey (7), New York (9), North Carolina (5) Ohio (6), and Pennsylvania (5) (*see Appendix B*). A review of these states reveals substantial differences in their use of MDS data. Not surprisingly, the most common uses are for survey and certification work. States can take the MDS data directly from their own state servers for this purpose. The next most common use is for rate-setting. For this use, data are obtained from the state server and transferred electronically or put on a portable storage device and physically moved to another server where the data are analyzed using one of the large statistical packages.

Overcoming Barriers to MDS Data Access

Requesting a DUA is one task, but it is soon followed by the need to access the MDS data, make queries of it, and interpret and report the findings. It is not easy for a single person wanting to use MDS data to simply start working with it. Procedures are needed for getting the data from the state server, storing it in another place, and then getting useful information from the database.

Staff in other states report relying on the rate-setting vendor or other vendors to supply information. For example, Kansas contracts with a private vendor to use MDS information in setting the "direct care" part of the nursing home rate. This same rate-setting vendor also has a contract with the survey and certification unit to manage the federal data system. With the approval of the survey and certification unit, the rate-setting vendor responds to MDS data queries from department staff, even if these are not rate setting related queries.

Some states, such as Kansas and Maine, have stable relationships with a university research group that provides the storage and data analytic tools to query and report of information. Other states use a private vendor with these capabilities. For example, with the approval of the state survey and certification unit, University of Kansas staff gets the MDS data from the rate-setting vendor and moves it to a secure university server, where it is analyzed using statistical query programs, such as SAS and SPSS. Working with their university partners, Kansas state staff has a much easier time getting the information needed.

Staff in states where these relationships do not exist have a disadvantage if they wish to use MDS data. New Jersey serves as one example. The Community Choice Counseling staff, which has been helping people transfer from nursing homes since 1998, considered using MDS to supplement their efforts. They did obtain a DUA, but did not implement it for nursing home transition because they do not have ready access to the

technology for processing MDS data. They could write the technical queries and submit those queries to the state's MDS Coordinator, who works with the federal server, but they have not developed an infrastructure for doing this. Since Community Choice Counseling staff is assigned to every nursing home in the state, as in Washington, they routinely counsel nursing home residents about their other long-term care options, and do not feel that they need to develop a MDS query infrastructure at this time.

Applications of MDS Data

Once the access, storage and query problems are solved, the MDS is broadly used. Sometimes demographic information, such as the addresses and age of resident, are used. In this respect, the MDS is being used as an alternative to getting residents' demographic data from the Medicaid Management Information System (MMIS). For example, the home location of the resident or the resident's age and length of stay in the nursing home can also be obtained from the MMIS. However, there is no other alternative way of obtaining resident-level data on the clinical and other MDS-specific questions, and MMIS systems only have information on Medicaid eligibles, not all residents.

Researchers interviewed reported some difficulties using the MDS. For example, different assessments require different MDS questions, and this makes comparison of responses more difficult to compare over time. In addition, working with multiple assessments over time can be confusing because admission and discharge data are not always continuous, making multiple stays difficult to track.

State Agencies' Use of the MDS for Nursing Home Transition

A nursing facility transition project seeks to identify persons within nursing homes who might prefer to live in the community rather than a nursing home. This is distinct from "diversion" projects that seek to maintain persons in their communities, rather than have them admitted to a nursing home. In federal fiscal years 2001 and 2002, CMS awarded 23 Nursing Facility Transition (NFT) grants to state agencies and ten grants to independent living centers.

There are approximately 500 independent living centers in the United States and they are funded from a combination of state, federal and private resources.[19] These centers are private, non-profit corporations that provide services to maximize the independence of individuals with disabilities and to promote accessibility to community living. The main federal source of funding for the centers is the Department of Education's Rehabilitation Services Administration. The federal funding requires the centers to provide "core services," including: advocacy; independent living skills training; information; and, referral and peer counseling. Transition and diversion activities are compatible with the staff philosophy, mission, and core services required of the centers. In fact, the Rehabilitation Services Administration's Form 704 asks centers to report on their transition work.

---

[19] Independent Living Centers (2006). For a list of centers by state, see: www.ilusa.com/links/ilcenters.htm.

The nursing facility transition grants generally ended between 2004 and 2006, depending on which year the grant was made and whether the grantee obtained a "no-cost extension" to use unexpended funds. A 2005 report of 18 grantees found that none of these states used the MDS as a resource to identify potential transition candidates.[20] To explore further, we contacted all 33 grantees during March and April of 2006. There has been substantial staff turnover in the last four to five years in the organizations receiving the grants, and conversations were held with subcontractors, former employees, new staff and others who could provide information about what happened during the grant. At least one person familiar with the transition work in each grant was contacted and asked about use of the MDS.

Among those states that have the most DUAs, there is modest progress in using the data for nursing home transition purposes, and its use has raised questions about which information can be shared, and about the timeliness of the information. We offer some examples here.

Kansas

Currently Kansas has two ways that help persons transition back to the community, and neither makes use of MDS data to identify these persons. However, Kansas is planning an enhancement program that will use MDS data.

One way persons are helped is through the Money Follows the Person (MFP) program. For the last two legislative sessions, Kansas has had a MFP program that is similar to the Texas MFP model. If a person wants to leave the nursing home, the state will transfer the average monthly nursing facility payment from the nursing home budget to pay for his or her home and community-based services. This transfer is primarily used for persons with physical disabilities who would have to be placed on a waiting list for waiver services without this MFP approach (It is easier for frail elders to receive waiver services). Assistance with transfers is offered at the request of nursing home residents. The main way that these individuals are identified is through Kansas' strong advocacy program, in which people with physical disabilities visit nursing homes and talk with residents.

Kansas does have another way to identify people for nursing home transition. The state does not have a formal nursing facility transition program. However, identification of residents and subsequent transition help is built into the state's Client Assessment and Referral Evaluation (CARE) Program, which is used in nursing home pre-admission screening and follow-up. The pre-admission screening contains a question that asks if the person wishes to leave the nursing home in 90 days, and then case managers conduct a 30-day and 90-day follow-up with the resident.

In addition to these non-MDS methods, Kansas is now planning an enhancement program to further help persons to leave nursing homes. About 3,000 to 4,000 nursing home residents in Kansas check "yes" to Section Q, indicating that that they would like to

---

[20] Siebenaler, O'Keeffe, Brown & O'Keefe (2005), p. 27.

leave the nursing home. State staff has had planning meetings and are now working on the use of the MDS to first identify those who respond "yes" for a secondary screening. The need for a secondary screening arises because many residents will express a preference to return to the community. Given this upward bias in the answers to Section Q, how can a state identify those residents who are seriously committed to transitioning back to the community? The state is now actively planning how to further screen these 3000 to 4000 people to develop a smaller list, so that staff from the area agencies on aging, the independent living centers, and nursing homes can work together to help the residents move back to their communities.

North Carolina

North Carolina's nursing facility transition program obtained a DUA and considered using MDS data to identify persons who wished to leave the nursing home. However, they found that not all of the community agencies working on the program, such as the Centers for Independent Living, had been named in the DUA, and there were issues raised as to the amount and kind of data that could be shared with outside agencies. State staff concluded that the use of LTC Ombudsmen, Centers for Independent Living, and provider education and information sessions were much better and more efficient ways to identify individuals for transitions.

Pennsylvania

Pennsylvania is making a concerted effort to help anyone who asks for assistance in transitioning. One of the state's DUAs supports its nursing home transition effort. To increase its outreach efforts, MDS data are sorted on the basis of impairment, and persons with low impairments are noted as additional candidates for transition efforts. The state has contracts with both area agencies on aging and independent living centers to perform the transition work. It takes two to three weeks to get the data to the contractors and the state may shorten the time by exploring a modest "pay for performance" rate increase for nursing homes that send the state their new MDSs within five days.

Uses of MDS Data by Nursing Facility Transition Grantees

Staff who worked on the 33 nursing facility transition grants mentioned three different uses of the MDS data: advocacy uses; work within a nursing home; and, creating a list of persons who might wish to transition from a nursing home.

The Use of MDS Q1a Answers as an Advocacy Tool

Two of the ten independent living centers, Alabama and Wyoming, and one state agency, New Hampshire, use statewide data on the number of persons who answered "yes" to the MDS Question Q1a: "Resident expresses/indicates preference to return to the community." Consumer advocates have frequently pointed out that over a quarter of a million persons, about 20% of the nursing home population, answered "yes" to this

question.[21] The CMS website records blank as "no" and persons using these answers should be alert to this reporting procedure. State-specific Q1a answers are used by advocates within the state to show how many persons want to leave nursing facilities and advocate for state action to make this possible.

Q1a information on states is available on the CMS website at http://www.cms.hhs.gov/apps/mds/q1a_start.asp, and the website of the Iowa Foundation for Medical Care has a page on MDS data on the age and Medicare status of persons who answered "yes" to Q1(a)by state and by county: http://www.qtso.com/mdsdownload.html.

The Use of MDS by Transition Workers Working in a Nursing Home

Grantees indicated that case workers and transition workers routinely looked at the MDS assessments of specific persons while working within the nursing home. The usual process is that the MDS is one of the data sources used to figure out what services a person would need to return to the community. The workers also talk with the resident, the nursing home staff, the family and other caregivers who have worked with the person.

A Wyoming transition worker reported a detailed description of which MDS questions are used. "I do use the MDS in every transition. I use the Medicaid/Medicare Number for working with waiver forms, I use the Ethnic background information, because we track this information for our quarterly reports, I use the Advanced Directives questions, so that we may share this information with Case Managers, I use the Responsibility section, so that I will know if the consumer has a guardian, I use the ADL information to track what the consumer daily living needs are….I use the Disease section, because we also track this for our quarterly report, and we use it for case management. I use Behavioral Symptoms, so that we may know some of the issues a consumer may be dealing with. I use the Discharge Potential questions, to know if this consumer has been determined to have the desire to transition and if they have a support person who also is positive towards discharge."

The Use of MDS to Generate a List of Names as Possible Referral for Transition Work

As discussed above, Pennsylvania has a routine process for generating lists of names of possible transition referrals. Georgia staff also reported using the MDS database to generate a list of names of persons who might be good candidates for transition work. Georgia has a DUA, gets quarterly MDS data and provides a list of possible referrals to a private contractor who sends nurses to do an assessment. Persons are selected to be on the list by an algorithm that looks at answers to section Q1, how long the persons have been in the home and the characteristics of their impairments.

---

[21] For example, see the information bulletins of Steve Gold, a disability advocate, available at: http://www.dimenet.com/actions/archive.php?mode=P&id=637

Maryland did not use the MDS for the nursing facility transition grant. However, the state did use it for its Option Counseling program under its Money Follows the Person legislation and implementation. Specifically, the state looked at question Q1a in terms of people that answered "yes" to the question. Nurses from the Delmarva Foundation, the state's contracted vendor, were provided the names of the individuals that responded "yes." The nurses would then meet with those individuals during their quarterly utilization review of the nursing facility. State staff reported that this was not an effective process, because about 90% of the individuals were no longer in the nursing home.

In late 2003 Nevada began supplying quarterly lists to its field offices in the FOCUS program. The FOCUS program is a Medicaid program that sends state workers called "transition navigators" into nursing homes. The list contains the names of Medicaid persons with MDS scores that had the Section Q answers checked, indicating that the person preferred to go home. The list does not contain Medicare or private pay. The list also contains other information from the MDS, including summary scores on cognition and Activities of Daily Living (ADL) answers, as well as the person's resource utilization score (RUG). Staff indicated that the list is very useful in generating referrals.

Why was the MDS Database Infrequently Used by the Nursing Facility Grantees?

We find that there are **six reasons why the MDS database has not been used** extensively to generate a list of names of nursing home residents who might be good transition candidates.

- **First**, **a majority of the projects said they didn't need the MDS to generate a list of referrals since they had enough other referral sources**.
  Almost all of the grantees who said they were not using the MDS indicated that they had other referral sources. Most reported that they had more than enough referrals from toll-free telephone numbers, the nursing homes themselves, word-of-mouth referral from nursing home residents, contacts made while working within the homes, and state staff who worked with nursing home residents and persons receiving Medicaid waiver services. For example, in Massachusetts the issue of using MDS did not come up. Rather, the project obtained a list of names of persons with low impairments from Mass Health, the state's Medicaid agency. Massachusetts uses a Medical Minutes Questionnaire (MMQ) which categorizes persons based on the number of minutes of care they need. H, J and K are at the lowest scale and persons in these groups have the least impairment and persons on the list were in these groups.

- **A second, major reason why the MDS was not used is because the transition projects were small.**
  Only two of the ten projects run by centers, those in Georgia and Wisconsin, transitioned more than 100 persons over a three-year period. The small scale of the projects means that a large number of referrals are not needed. **Only three of the 23 state projects, Michigan, Washington**

and Wisconsin, transitioned more than 300 persons over the three-year period.[22] A majority of state projects were also small and reported no difficulty obtaining referrals.

Four states are using MDS substitutes. Michigan used the MDS-HC instrument, which has a substantial overlap with the MDS, but does not require a DUA. Transition workers in the nursing homes would interview residents using the MDS-HC and this information would be added to the rest of the information collected about the resident. Louisiana is using an MDS-Community Screener, which is a shortened version of the MDS. The use of these alternatives avoids perceived difficulties in applying for a DUA and then getting access and analyzing MDS assessments.

North Carolina staff report that they have decided to build transitions and consumer-directed questions/evaluations into their Internet-based uniform screening/program admission process that is under development. In its new Nursing Facility Transition and Diversion Waiver, New York is planning to use the Patient Review Instrument (PRI), the purpose of which is described in the wavier as "to identify medical events including: medical conditions and treatments; capabilities of the individual to perform Activities of Daily Living (ADLs); behavioral difficulties; and, specialized services which will result in the potential waiver participant's level of care."[23]

- **Third, some nursing facility transition projects operated by non-profit community groups, such as independent living centers, reported that they want to access the MDS data, but state agencies were reluctant to provide the access.**

  Comments about "release of information" concerns were made by state staff and persons in non-profit agencies in four states. This issue has been percolating for four to five years since nursing facility transition efforts were broadly begun in the states.[24]

- **Fourth**, **nursing facility transition projects lack the technology to acquire and process MDS data.**

  Appendix B contains examples of the technology employed by current users of MDS. Discussions with staff in the independent living centers indicate that many have only three to five staff members and that they do not have the technological capabilities developed by big state agencies, university research centers, or private vendors. State home and community-based care agencies or divisions on aging can also be small

---

[22] Siebenaler, O'Keeffe, Brown & O'Keefe (2005, June). See Exhibit B-1.

[23] New York State Department of Health (2006). A copy of the wavier can be found at http://www.health.state.ny.us/facilities/long_term_care/

[24] Steve Gold's Treasured Bits of Information (2006). For example, see http://www.stevegoldada.com/stevegoldada/archive.php?mode=A&id=119;&sort=D

operations and need to solve the same technology problems as independent living centers.

- **Fifth, in addition to reasons cited above, some state staff expressed reservations about the difficulty of obtaining a DUA.**
    There is a perception that obtaining DUAs is difficult and/or lengthy, or that if you did obtain a DUA it may require changes. Given that there are over 260 active DUAs, these comments may reflect experiences from earlier time periods or local conditions. However, some found that there was no difficulty obtaining DUAs beyond the usual ones included in writing and submitting a request for the DUA.

- **Sixth**, **some stakeholders expressed reservations about the limits in the MDS items themselves, and how fast the information aged**.
    Concerns about the validity of preference questions and how accurately they measure a person's desire to live in the community do exist. There is also concern about the reliability of the information and how quickly it can change over time, especially given the time lags between when the assessment is completed and when the transition program gets the information.[25]

These reservations indicate that state transition policies might be strengthened by securing MDS results as soon as possible after the MDS is filled out, or by focusing primarily on persons who are residents of nursing facilities for periods of 45, 90 or 180 days. A focus on persons with a longer stay would sort out persons who may leave earlier because they are Medicare persons admitted for post hospitalization rehabilitation. However, if options-counseling is not provided for 6 months, many nursing home residents will have difficulty reestablishing a community living situation. The use of secondary screening processes such as those being studied in Kansas is also a useful next-step in working with Section Q data.

Suggestions for Strengthening the MDS

Since the MDS is a required assessment, it can be used to emphasize to nursing home staff and residents that living in the community with services is one long-term care option for consumers. If used in a timely and consistent way, the MDS tool and process can help identify those who may want to transition back into the community and start the discharge process.

To accomplish these goals, we identified several suggestions for changing existing MDS questions or for adding new ones. Most relate to Section Q. The current wording of Section Q is shown below:

---

[25] Eiken, Hatzmann & Asciutto (2003). See comments about Vermont's experience with MDS timeliness of data in "One-to-One: Vermont's Nursing Home Transition Program," at:
http://aspe.hhs.gov/daltcp/reports/VTtrans.pdf .

Figure 1: Section Q. Discharge Potential and Overall Status

1.	DISCHARGE POTENTIAL	a. Resident expresses/indicates preference to return to the community 0.No 1.Yes	
		b. Resident has a support person who is positive towards discharge 0.No 1.Yes	
		C. Stay projected to be of a short duration-discharge projected within 90 days (do not include expected discharge due to death) 0.No 2.Withing 31-90 days 1.Within 30 days 3.Discharge status uncertain	

2.	OVERALL CHANGE IN CARE NEEDS	Resident's overall self sufficiency has changed significantly as compared to status of 90 days ago (or since last assessment if less than 90 days)
		
		0.No change 1.Improved-receives fewer 2.Deteriorated-receives
		                        supports, needs less more support
		                        restrictive care	

Suggestions for change include:

- Move up the discussion of discharge preferences to the beginning of the MDS, before the person suffers "interview fatigue." Giving Section Q more visibility and emphasis would get the attention of those who are conducting the MDS.

- Make the completion of section Q mandatory for the first full assessment, the quarterly and annual assessments, and whenever a consumer completes the post-acute Medicare stay.

- Add more detail under Section Q 1a, including questions about current housing. One specific recommendation is to incorporate referral questions from Section CC and living arrangement questions from Section O of the MDS-HC assessment form.

- Add to Section Q a question about the person's desire to talk to someone about the possibility of returning to the community. Having the person's permission to give his or her name to an area agency on aging or a center for independent living would be particularly helpful to overcome concerns about sharing confidential information.

- In the instructions for completing the MDS, clearly require that staff ask the resident the Section Q questions, not just fill out the Section Q without talking to the resident and indicating what the staff thought the resident would say.

- Consider adding a measure of the intensity of the preference for returning to the community by rating each on a scale from a weak to a strong preference.

- If a person does express a preference, include a "trigger" for a mandatory follow up. This is an important issue since it addresses what happens after a person indicates a preference to be in the community. Currently, nothing may happen. There is no process in place for following up on these choices. This lack of a process occurs in a context of confidentiality concerns that inhibit sharing of names of persons who answer "yes" to question Q1a., and timeliness concerns on how fast these persons can be called to the attention of transition workers.

- Ask those residents who express a preference to return to the community what they would like to do to make this happen. These would be in the form of a checklist of actions that could be taken.

- A more substantial change would be to incorporate some items designed to serve person-centered planning, such as:

  - What is your goal for your nursing facility stay (e.g., short-term rehab and return to home, stabilize medical condition and return to home, recover specific ADL skills and return to home, etc.)?

  - What community activities were most important to you prior to your admission?

  - What family activities were most important to you prior to admission?"

The recommendations above directly address the validity and timeliness of using the MDS data to assist in identifying persons who might be able to transition to a community placement. Better measurement of the person's choice of a community placement and the creation of a process for following-up on the resident's choices would be a considerable step forward in helping states and transition programs.

From a policy perspective, these changes could help federal and state officials and their partners track national and state patterns related to nursing home admission and discharge. Ideally, the MDS would have sufficient information to identify the nursing home length of stay at various points and to distinguish payer sources. As a start, it would be helpful to carry over the initial date of admission/MDS data entry onto every assessment. This date should be included routinely on the discharge tracking form. Finally, it would be very useful to include checkboxes for insurance coverage available, or at least for Medicaid (i.e., yes, no, pending) on the basic assessment tracking form and the discharge tracking form.

Conclusion

There is continuing interest in using the MDS to facilitate nursing home transitions for those who want to return to their homes and communities. Limitations in the MDS and barriers in using the information can be overcome. The MDS cannot replace consistent outreach to consumers, but it can augment those efforts and support policy and program development at both the federal and state levels.

Acknowledgements

Appendix A: Data Use Agreements

Obtaining federal health care data requires Data Use Agreements. The use of such agreements is now extraordinarily widespread. In response to The Health Insurance Portability and Accountability Act of 1996 (HIPAA), the U.S. Department of Health and Human Services (HHS) issued the regulations implementing HIPAA in August 2002. These regulations were called *Standards for Privacy of Individually Identifiable Health Information*. For most covered entities, compliance with these regulations, known as the Privacy Rule, was required as of April 14, 2003. HIPAA and its implementing regulations were the first federal national standards and protection for the privacy of personal health information.

HIPAA and its implementing regulations created a common methodology and vocabulary for describing how access to health care information should be done. As part of this HIPAA context, the process of using Data Use Agreements and the term "Data Use Agreement" came into widespread usage. It is now used by all components of the federal Department of Health and Human Services (HHS) and its Center for Medicare & Medicaid Services (CMS) to release information from major CMS databases, such as the Surveillance, Epidemiology, and End Results (SEER)-Medicare database, the Medicare Enrollment Database (EDB), Medicare Provider Analysis and Review database (MEDPAR), and other Medicare claims databases such as Hospice, Outpatient, and Durable Medical Equipment.

States such as Florida[26], Texas[27], and Wisconsin[28] have adopted mirror images of the federal DUA language and process.

Universities and medical schools are significant users of MDS data, with about 72 (27%) of the 262 active DUAs. The largest university users are Brown with 18 DUAs, Texas A&M with seven, and the University of Missouri at Columbia with five. The universities of Minnesota and Wisconsin have three DUAs apiece, and another 32 universities and medical schools each have one or two DUAs.

Extensive use of MDS data has been made by researchers studying quality indicators for nursing homes.[29] University-based researchers have created a sizeable literature using MDS data to link assessments, Medicare claims, nursing facility programs, and outcome characteristics.[30, 31, 32]

---

[26] Florida Agency for Health Care Administration (2003).
[27] Texas Department of State Health Services (n.d.).
[28] Wisconsin Health Care Information (2005).
[29] Capitman, Leutz, Bishop & Casler (2005).
[30] Intrator, Zinn & Mor (2004).
[31] Avidan, Fries, James, Szafara, Wright & Chervin (2005).
[32] Bates-Jensen, Simmons, Schnelle & Alessi (2005).

Appendix B: How States Store, Transfer and Analyze MDS

Below we present information about those states with the most DUAs. Seven states have five or more DUAs: Kansas (5), Maryland (5), New Jersey (7), New York (9), North Carolina (5) Ohio (6), and Pennsylvania (5). In the discussion below we have also included a summary of Maine's two DUAs because of the unique uses being made in its MDS approach.

The descriptions show both the uses that are made of the MDS, as well as the various logistics used to store, transfer, and analyze data. They illustrate that established uses have a technological infrastructure that is often missing in new state projects and small non-profit agencies, such independent living centers. It is difficult for nursing facility transition programs to use MDS data unless they have access to this technological capability.

Kansas
The five Kansas DUAs have generally written reasons for using MDS data. For example, potential uses discussed are cost-effectiveness, quality, and helping Americans with Disabilities Act (ADA) activities. The Kansas Department of Aging makes broad use of MDS data to support its programs. The MDS is used in nursing home rate-setting, in licensing and certification of nursing homes, and for research on nursing home residents and facilities. The state uses a case-mix nursing home reimbursement and contracts with a private vendor to use MDS information in setting the "direct care" part of the nursing home rate. This same rate-setting vendor also has a contract with the survey and certification unit to manage the federal data system. With the approval of the survey and certification unit, the rate-setting vendor also responds to MDS data queries from Department staff for data related to these other reasons.

The Department of Aging has a contract with the University of Kansas for general research support involving the analysis of MDS data.[33],[34] In general, university researchers respond to queries from the Department of Aging for information. In the past, these queries have entailed looking at section Q of the MDS. The university is starting a longitudinal study of symptom-management in nursing facilities. For example, examining how pain management is impacted by staff turnover, staff levels, and type of management at the facility. The university also supports nursing home diversion efforts. With the approval of the survey and certification unit, university staff gets the MDS data from the rate-setting vendor and moves it to a secure university server, where it is analyzed using the statistical query programs SAS and SPSS.

---

[33] Forbes-Thompson, Dunton, Gajewski, Wrona, Becker, Chapin, Rachlin, Lee & Zimmerman (2003) The MDS was one of seven databases that were combined in a study of regional variations in reported nursing homes deficiencies.
[34] Chapin, Rachlin & Swaim (2002).

Maine

Maine does not use MDS data in its nursing facility transition work. The state has a contract with the Muskie School of Public Service at the University of Southern Maine. Muskie staff provides data analysis for the MDS, Outcome and Assessment Information Set (OASIS), RAVEN and other databases associated with the state's licensing and survey unit. Considerable use is made of the MDS in the state's case-mix, rate-setting and in providing management reports, such as admission discharge and census data. However, Muskie does not routinely use Section Q or other data to generate lists of referrals for nursing home transitions efforts.

Maine staff has had long experience with the MDS. It was a case-mix state in 1989 and in the mid- to late-nineties, state staff worked with providers to develop two new tools based on the MDS: one for assisted living called the MDS-ALS, and the other for residential care, the MDS-RCA. These instruments are used to assess persons' eligibility for services, develop care plans, and conduct quality assurance. The instruments have reimbursement groupers that assign persons with certain answers to reimbursement levels. Assisted living and residential care providers receive a payment based on the level to which the person is assigned. The Muskie School of Public Service's website at http://muskie.usm.maine.edu/mds/ describes these instruments in detail. For example, the website shows the quality indicators for residential care based on specific questions from the MDS-RCA.

CMS stores the MDS information the same way in each state. Muskie uses a Microsoft Access and OBDC links to take data from the Oracle tables in the federal MDS server located in Maine. This is a commonly found access method used by states to solve the technology problems of obtaining access to the MDS data. OBDC is an acronym for Open Database Connectivity. It is a standard database access method, which makes it possible to access any data from any application, regardless of which database management system is handling the data. The query is done on the federal computer before the data is taken. Before taking the selected data, as per federal procedures, the only data change the state might make is to run a MDS grouper that populates a Resource Utilization Score (RUGS) score in a field in the state's part of the MDS. This is allowed in federal regulations. Then the data is taken out of the federal server and moved to a state server for analysis.

Maryland

Maryland did not use the MDS for the nursing facility transition grant. However, it did use it for its Option Counseling program under its Money Follows the Person legislation and implementation. Specifically, the state looked at question Q1a in terms of people that answered "yes" to the question. Nurses from the Delmarva Foundation, the state's contracted vendor, were provided the names of the individuals that responded "yes" and would then meet with those individuals during their quarterly utilization review of the nursing facility. State staff reported that using quarterly data was not an effective process, because about 90% of the individuals were no longer in the nursing home.

The Maryland Health Care Commission (MHCC) gets annual data from CMS on a 3490 tape cartridge. This tape cartridge comes with about 250,000 Maryland records dating back to 1999. The commission stores the MDS data in a secure server while it is available for data analysis. The main access program used at the commission is SAS, although commission staff report that any statistical research program can be used with it.

The commission entered into a contract with private vendors to use MDS data to assist its Long-Term Care Division staff in planning and policy development, for example, in its bed-need methodology. The MDS is used to obtain ages, length of stay, days in the nursing homes, and geographical residence for use in projecting the need for nursing home beds in certification of need (CON) analyses.[35]

The commission also uses MDS data to compare Quality Indicators (QIs) across the state's nursing homes. The commission's website for consumer guides is at http://mhcc.maryland.gov/consumerinfo/index.htm, where you can click on the nursing home guide. For each home, the guide shows the home's ranking on 14 CMS quality indicators. After data analysis is complete, the data is stored in a secure off-site location.

New Jersey
New Jersey has seven DUAs. The nursing facility transition program has a DUA, but is not obtaining MDS since it has not obtained access to the technology for processing MDS data. The state's MDS Coordinator reports that state units that have a DUA can submit their queries to the survey and certification unit persons who work with the federal server, but survey and certification persons will not write the query for them. The nursing home rate-setting methodology uses MDS data. The Department of Health and Senior Services has a Center for Health Statistics that four years ago started a DUA to look at nursing home falls as part of it injury surveillance program. The survey and certification unit has a DUA and uses MDS information when it makes a survey visit to a nursing home.

New York
New York does not have current plans to use the MDS in its new Nursing Facility Transition and Diversion Waiver that it submitted on December 12, 2005 to CMS. On October 19, 2004, Governor Pataki signed into law the Nursing Home Transition and Diversion (NHTD) bill, authorizing DOH to apply for a new Medicaid waiver for enhanced nursing home transition and diversion activities. The state is now in a bidding process to select contractors for this transition work.

The state of New York has nine Data Use Agreements with CMS. Two of these are with the Medicaid Fraud Control Unit (MFCU) of the Attorney General's office. The unit gets a quarterly "bulk file transfer" from the state server. It comes as a set of Oracle tables and data is extracted using the Discoverer program, a part of the Oracle suite of software tools. Auditors and investigators use the MDS to get additional information about those nursing homes where abuse or neglect situations are thought to exist.

---

[35] Maryland Health Care Commission (2005).

Five of New York's DUAs are with the New York Department of Health. For example, the chronic disease epidemiology unit does public health surveillance of Alzheimer's and related cognitive problems. In order to obtain estimates of the prevalence of Alzheimer's, it uses the state's hospital discharge databases and examines MDS data on the state's nursing facilities. It uses Section I, looking at Alzheimer's and other dementia answers, as well any ICD-9 codes that are entered, and also uses Section B and its cognition questions. The unit identifies three times as many Alzheimer's cases using MDS than are reported manually using the old paper reporting forms.

Epidemiology staff gets the data from the state server on a CD in the form of a SAS dataset with assessments from 1999 to 2003. Staff reports the data is not easy to use, since different types of assessments ask different questions. For example, answers can be blank because that is how the person responded, or answers can be blank because the questions were not asked on that assessment. The same person can have different assessments over time, and study procedures need to control for the multiple assessments.

New York rate-setting staff had a DUA for a one-time study of the crosswalk between the MDS and the state's Patient Review Instrument (PRI). This state-developed case-mix instrument assigns persons to one of fourteen reimbursement groups and has been used since 1986. Rate-setting staff compared PRI results with results from using the MDS to assign persons to one of the fourteen groups. Staff decided that the study was inconclusive, because nursing homes would report different data for the same person for the same time period.

North Carolina

Of North Carolina's five DUAs, one helps the state's nursing home rate-setting vendor. Two of the DUAs are for the nursing home audit group. The nursing facility transition program obtained a DUA and considered using MDS data to identify persons who wished to leave the nursing home, but concluded that the use of LTC Ombudsmen, Centers for Independent Living, and provider education/information sessions were better and more efficient ways to identify individuals for transitions. Auditing compares the case-mix information reported on the cost report with data from the rate-setting vendor, who analyzes the MDS information for the state and calculates the quarterly case-mix index (CMI). The vendor sends the information to the nursing facility and to the audit unit. This is the only use the audit group makes of MDS information.

Ohio

Discussions with Ohio staff did not identify any use of the MDS in a nursing facility transition project. The Ohio Department of Aging has three of the state's six DUAs. The main use is for a longitudinal study that began in 1993. The Department is looking at the characteristics and claims of persons in nursing facilities and home and community-based settings. This is a joint project with Scripps Gerontology Center at Miami University. The Department of Aging gets the data every six months from the Department of Health on a diskette with a DVD format. Scripps receives the data and stores it on a university server where SAS statistical program is used to query the data.

For example, the department studied all nursing home admissions made during the summer of 2001, tracked the persons over time, and looked at average length of stay, spend down patterns, and when people became Medicaid eligible. To see the kind of analyses being made on this MDS data, explore the publications of the Scripps Gerontology Center. For example, from a 2006 study they concluded, "In tracking all first time admissions to Ohio nursing homes between 2001 and 2004, we found that after three months only 43% of all those admitted continue to reside in a nursing home. By 6 months less than one third of all those admitted continue to reside in a nursing home."[36,37]

The Department of Aging briefly used MDS information to calculate quality measures and to report them in a consumer guide, but staff said changing federal reporting categories made such use cumbersome.

The Ohio Diabetes Prevention and Control Program used the MDS for a one-time study of the prevalence of diabetes and its co-morbidities among persons in the state's 940 nursing homes. The DUA was obtained in 1999. The data was provided on a CD by the data processing persons who work with the state server. It was put on a personal computer and analyzed using PC SAS. It took two years to clean the data because there was no way to validate the data, and different MDSs done over time on the same person had contradictory information. A longitudinal study was difficult because of the frequent admissions and readmissions. The study was published and found that 25% of the 161,000 persons admitted to a nursing home during 1999 had diabetes, and that the MDS was useful in identifying important co-morbidities.[38]

Ohio also uses the MDS in licensing and survey work among nursing facilities, and state staff use the MDS in the state's rate-setting. State Medicaid staff gets the MDS data weekly from the state server, moves it to another server, and runs a "grouper" on it to calculate Resource Utilization Group (RUG) scores for use in establishing an average level of acuity for each of the nursing homes.

Pennsylvania

Pennsylvania has five DUAS and uses MDS in its nursing facility transition work. One is used by the state and a private vendor for case-mix rate setting. However, requests for data analysis from all of the five DUAs come through the MDS Automation Coordinator, who sends them to the private vendor. The vendor takes MDS data directly from the state's federal server. The DUA data is not analyzed on the federal server since CMS procedures are clear in stating that the state should not add anything to the federal server in addition to the MDS data. Rather it is taken directly from the federal server and moved someplace else. The coordinator reports that the process works well and there are no difficulties in getting access to the data.

---

[36] Mehdizadeh, Nelson & Applebaum (2006).
[37] Mehdizadeh & Applebaum (2005).
[38] Duffy & Zack (2005).

The Bureau of Long-Term Care, within the Office of Medical Assistance, has two DUAs. Staff at the bureau use Microsoft Access and ODBC links to get the MDS data from the server of the state's rate-setting case-mix vendor. Similar to Kansas, the rate-setting vendor also has a contract with the state's survey and certification unit to manage the MDS data, and it releases data with that unit's approval. The bureau's first DUA was a general one that supports long-term care licensing and nursing home bed approvals, as well as general queries. They use the MDS data to help them make licensing approvals of requests to add nursing home beds. For example, the MDS is used to identify the home addresses of persons in nursing facilities, and to see how many persons live in one area but get their care in another area. These data are useful in seeing if an area lacks sufficient beds for local demand. An example of a general policy query is to collect data on when persons become eligible for Medicaid, relating whether it is their first day in the nursing home or whether the person is spending down their resources.

The bureau's second Data Use Agreement supports its Health Care Reform unit and its nursing home transition effort. That data is sorted on the basis of impairment, and persons with low impairments are noted as possible candidates for transition efforts. The bureau has contracts with both AAA and independent living centers to perform the transition work. It takes two to three weeks to get the data to the contractors, and the bureau is shortening the time by getting a modest "pay for performance" rate-bump for nursing homes that send the state their new MDSs within five days.

References

Avidan, A.Y., Fries, B.E., James, M.L., Szafara, K.L., Wright, G.T., & Chervin, R.D. (2005). Insomnia and hypnotic use, recorded in the Minimum Data Set, as predictors of falls and hip fractures in Michigan nursing homes. Journal of the American Geriatrics Society, 53, 955. Retrieved on June 7, 2006, from http://www.blackwell-synergy.com/links/doi/10.1111/j.1532-5415.2005.53304.x/abs/.

Bates-Jensen, B.M., Simmons, S.F., Schnelle, J.F., Alessi, C. (2005). Evaluating the accuracy of Minimum Data Set bed-mobility ratings against independent performance assessments: Systematic error and directions for improvement. The Gerontologist, 45, 731-738. Retrieved on June 7, 2006, from http://gerontologist.gerontologyjournals.org/cgi/content/abstract/45/6/731

Capitman, J., Leutz, W., Bishop, C, & Casler, R. (2005). Long-term care quality: Historical overview and current initiatives. Report for the National Commission for Quality Long-term Care. Retrieved on June 7, 2006, from http://qualitylongtermcarecommission.org/reports/pdfs/txBackground03-10-05FINAL.pdf"

Centers for Medicare & Medicaid Services. (2006, April 21). MDS 2.0 for nursing homes: MDS 2.0 manuals and forms. Retrieved May 19, 2006, from http://www.cms.hhs.gov/NursingHomeQualityInits/20_NHQIMDS20.asp#TopOfPage

Chapin R, Rachlin, R & Swaim, T. (2002, June 30). Older adult client outcome indicator project report: Fiscal year 2002. Prepared for the University of Kansas, School of Social Welfare, Office of Aging and Long-Term Care, supported through a contract with the Kansas Department on Aging and Kansas Department of Social and Rehabilitation Services, Topeka, Kansas. Retrieved on June 7, 2006, from http://www.socwel.ku.edu/oaltc/Reports/OutcomeIndicatorReport2002.pdf

Eiken, S., Hatzmann, M. & Asciutto, A.J. (2003, December 19). One-to-one: Vermont's nursing home transition program. Prepared for Gavin Kennedy, Dept. of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy. Washington, DC: Medstat. Retrieved May 19, 2006, from http://aspe.hhs.gov/daltcp/reports/VTtrans.pdf.

Florida Agency for Health Care Administration, State Center for Health Statistics. (2003, August). State Center for Health Statistics: 2002 annual report. Retrieved June 7, 2006, from http://www.floridahealthstat.com/publications/schs_ar2002.pdf.

Forbes-Thompson, S, Dunton, N., Gajewski, B., Wrona, M., Becker, A., Chapin, R., Rachlin, R., Lee R., & Zimmerman, M. (2003, December). Kansas nursing facility project evaluation. Report prepared for the Kansas Department on Aging. Retrieved on June 7, 2006, from http://www.nursingoutcomes.org/year_1_report.pdf.

Duffy, R., Mattson, B. & Zack, M.J. (2005). "Co-morbidities among Ohio's nursing home residents with diabetes. Journal of the American Medical Directors' Association, 6, 383-389.

Gold, M. (2006, April 10). Texas promoting independence initiative: Money follows the person. Presentation at the annual CMS New Freedom Initiate Conference, Transforming Systems: Keys to Success, Baltimore, Maryland.

Hamilton, T.E. & Arden, G. (2005, February 18). Release of the 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. Department of Health & Human Services, Centers for Medicare & Medicaid Services. Baltimore, Maryland. Retrieved on June 7, 2006, from http://www.hcbs.org/files/59/2936/MDSFINAL1.DOC.

Independent Living Centers (IL USA). (n.d.). Retrieved May 19, 2009, from http://www.ilusa.com/links/ilcenters.htm.

interRAI. (n.d.) Retrieved on May 19, 2006, from http://www.interrai.org/section/view/?fnode=31

Intrator, O., Zinn, J. & Mor, V. (2004). Nursing home characteristics and potentially preventable hospitalizations of long stay residents. Journal of the American Geriatrics Society, 52(10), 1730-1736. Retrieved on June 7, 2006, from http://www.blackwell-synergy.com/doi/abs/10.1111/j.1532-5415.2004.52469.x?journalCode=jgs

Justice, D. & Heestand, A. (2003). Promising practices in long term systems reform: Oregon's home and community-based services system. Washington, D.C: Medstat.

Maryland Health Care Commission. (2005, November). An analysis of future need for nursing home beds in Maryland: 2010. Baltimore, Maryland. Retrieved on June 8, 2006, from http://mhcc.maryland.gov/longtermcare/analysisnhbmd.pdf

Mehdizadeh, S.A., Nelson, I.M. & Applebaum, R.A. (2006, February). Nursing home use in Ohio: Who stays, who pays. Scripps Gerontology Center, Brief Report. Oxford, Ohio: Miami University. Retrieved on June 8, 2006, from http://casnov1.cas.muohio.edu/scripps/publications/documents/FinalNHuse.pdf.

Mehdizadeh, S. & Applebaum, R. (2005, March). A review of nursing home resident characteristics in Ohio: Tracking changes from 1994-2004. Oxford, Ohio: Scripps Gerontology Center, Miami University. Retrieved on June 8, 2006, from http://casnov1.cas.muohio.edu/scripps/publications/documents/Review_NH_Characteristics.pdf

Mollica, R. (2005). Building nursing home transition into a balanced long term care solution: The Washington model. New Brunswick, New Jersey: Rutgers CSHP/NASHP Community Living Exchange. Retrieved on June 8, 2006, from http://www.cshp.rutgers.edu/cle/products/WAsitevisitsummaryfinalLPWEB.pdf and www.hcbs.org.

Mor, V. (2004, June 25). National long-term care databases: Clinical assessment tools with research and policy applications. Workshop on the Analysis of Centers for Medicare and Medicaid Services Data by the National Institute on Aging, Behavioral and Social Research Grantees, Baltimore, Maryland.

New York State, Department of Health. (2006, May). Retrieved on June 8, 2006, from http://www.health.state.ny.us/facilities/long_term_care/.

Reinhard, S., Hendrickson, L., & Bemis, A. (2005). Using the Minimum Data set (MDS) to facilitate nursing home transition. New Brunswick, New Jersey: Rutgers/NASHP Community Living Exchange. Retrieved on June 8, 2006, from www.hcbs.org and http://www.cshp.rutgers.edu/cle/products/MDS_Final_WEB.pdf.

Reinhard, S. & Petlick, N. (2005). Sustaining New Jersey's evolving Community Choice Counseling program. New Brunswick, New Jersey: Rutgers/NASHP Community Living Exchange. Retrieved on June 8, 2006, from http://www.cshp.rutgers.edu/cle/Products/NJCCCWEB.pdf and www.hcbs.org.

Siebenaler, K., O'Keeffe, J., Brown, D. & O'Keeffe, C. (2005, June). Nursing facility transition initiatives of the fiscal year 2001 and 2002 grantees: Progress and challenges. Research Triangle Park, NC: RTI International.

Steve Gold's Treasured Bits of Information. (2005, February 22). CMS announcement re. MDS data and the ADA (Article 119; Category Nursing). Retrieved on May 19, 2006, from http://www.stevegoldada.com/stevegoldada/archive.php?mode=A&id=119;&sort=D

Texas Department of State Health Services, Texas Health Care Information Collection Center for Health Statistics. (n.d.). Data use agreement hospital discharge data research file. Retrieved on June 7, 2006 at http://www.dshs.state.tx.us/THCIC/Hospitals/ResearchDataUseAgreement.htm

Tucker, A.M. & Decker, F.H. (2004, July 2). Using long-term care MDS data: Patient days and case mix. Washington, DC: American Health Care Association, Health Services Research and Evaluation.

Wisconsin Health Care Information, Department of Health & Family Services. (2005, December). Physician office visit (Data collected under Chapter 153, Wis. Stats.) Retrieved on June 7, 2006 from http://dhfs.wisconsin.gov/healthcareinfo/pov/datarelease.htm

Washington State Department of Health and Social Services, Office of Rates
Management. (2003, October). Medicaid nursing facility payment system: Impacts
of case mix methodology to access, quality of care and quality of life for nursing
facility residents. (Report to the Legislature, Chapter 8, Laws of 2001, E1 Section
18(2)). Retrieved on May 19, 2006, from
http://www1.dshs.wa.gov/pdf/EA/GovRel/Leg1203/MNFPS1203.pdf.