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# Discussion Paper

## Community Living Exchange

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The Minimum Data Set:  
Recommendations to Help States  
Better Support Nursing Home  
Residents Who Seek Community Living

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**June 2007**

**Discussion Paper**

**The Minimum Data Set: Recommendations to Help States Better Support Nursing Home Residents Who Seek Community Living**

**Susan C. Reinhard and Leslie Hendrickson**

**Summary**

This Discussion Paper summarizes the background and recommendations for potential changes to make the Minimum Data Set (MDS) and related policies and practices more useful to states for identifying and supporting nursing home residents who wish to return to their homes and communities. Section Q of the MDS has, for some years, been discussed at state and national conferences, training sessions, on conference calls, during technical assistance visits, and in talks among state Medicaid staff. For example, Rutgers Center for State Health Policy has worked on this since 2002 and has published two reports that discussed Section Q.<sup>1</sup>

Based on the authors' synthesis of these discussions, this Discussion Paper links the momentous changes of the New Freedom Initiative policies with the need to upgrade or modernize the MDS to better reflect these policies. Four opportunities for improvements are recommended to improve discharge planning in the country's 15,885 nursing homes.<sup>2</sup>

**Major Points**

- Following the Olmstead decision, massive and far-reaching federal policy initiatives attempt to provide more choice, dignity and independence for persons with disabilities. One clear goal of these policies is to help such persons live and work in the community outside of institutions.
- Section Q of the MDS is not supportive to states implementing transition programs. Section Q does not support persons who express a preference to leave institutions. For example, the lack of monitoring of institutional reactions to patients' Section Q responses is perceived to be a serious weakness in the assessment of resident need and resident choice of long-term care services. The

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<sup>1</sup> Reinhard S., Hendrickson L., & Bemis A. (2005, February) and Reinhard S. & Hendrickson L. (2006, June).

<sup>2</sup> American Health Care Association. (2006, December), *OSCAR data for December 2006*. Retrieved on March 19, 2007 from [http://www.ahca.org/research/oscar/rpt\\_control\\_200612.pdf](http://www.ahca.org/research/oscar/rpt_control_200612.pdf)

fact that a resident might wish to leave the nursing home is not considered a priority in the operation and oversight of institutions.

- Section Q is one of the few sections in the MDS manual whose answers are not used in a RAP. Adding a 19<sup>th</sup> RAP is seen by states and advocacy organizations as critical to support CMS New Freedom Initiative policies.
- The Section Q instructions in the MDS Users Manual are viewed by states and advocacy organizations as paternalistic and inconsistent with CMS NFI policies. The wording should be reviewed and revised to create an expectation for an objective assessment of resident preferences and eliminate the suggestion to pre-judge the resident's ability to successfully transition.
- Persons discussing Section Q items often cite difficulties with the current wording of the items and suggest the rewriting, elimination, or adding of items. These difficulties and suggestions are discussed at length below.
- Adding Section Q to the MDS Quarterly Assessment would be useful given states efforts to obtain timely information on resident's preferences.

## **Background**

Section Q items in the Minimum Data Set (MDS) have been extensively discussed by state Medicaid staff, consumer advocates seeking to help persons leave nursing homes, and federal staff of the Centers for Medicare & Medicaid Services (CMS). For example, Section Q has been discussed at conferences such as the annual conferences of Home and Community Based Services, Rutgers/NASHP learning collaborative meetings with CMS grantees,<sup>3</sup> and CMS New Freedom Initiative conferences. Discussions of Section Q are often imbedded in discussions of nursing home transition programs,<sup>4</sup> resident assessments, and discharge planning. But these discussions also occur in the context of massive and significant federal policy initiatives and states' efforts to accomplish these initiatives.

### **The Federal Policy Background Emphasizes Choice in Long-Term Care Services**

The 1999 *Olmstead vs. L.C. and C.W.* decision facilitated a landmark change in Federal long-term care policy.<sup>5</sup> The New Freedom Initiative (NFI) was announced by President George Bush on February 1, 2001 and followed up by Executive Order 13217 on June 18, 2001. Congress supported this major policy change by authorizing the Real Choice System Change program which, since its inception in FY2001, has awarded 314 grants totaling over \$280 million to all fifty States, the District of Columbia, and two territories. Thirty-one "Money Follows the Person" grant awards issued by CMS in 2007

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<sup>3</sup> The Rutgers/NASHP technical assistance team has held a series of "MFP Systems Design Collaboratives" in New Jersey, Washington, Texas, and California; participant discussion on the MDS at each of these forums is incorporated in this discussion paper.

<sup>4</sup> Centers for Medicare & Medicaid Services, (2006, July).

<sup>5</sup> The Supreme Court text of the decision can be found at <http://supct.law.cornell.edu/supct/html/98-536.ZS.html> and an overview of the background of the June 22, 1999 Supreme Court decision can be found at <http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm>

will support the transitions of more than 37,000 people back to their homes and communities. Additionally, in collaboration with the Administration on Aging (AoA), CMS has awarded 43 Aging and Disability Resource Center grants of up to \$800,000 each to help States develop one-stop shopping centers for seniors and people with disabilities who need long-term care information.<sup>6</sup> CMS has also sponsored Direct Service Worker grants, Medicaid Infrastructure grants and the Demonstration to Maintain Independence in Employment.

The momentum built by these continuing, intensive federal policy changes is shown in the waivers--139 of section 1915(c) and 8 Independence Plus--that were approved by CMS in FFY 2006.<sup>7</sup>

The Deficit Reduction Act of 2005 (P.L. 109-171), hereafter DRA, was passed in February 2006 and added to the momentum created by earlier New Freedom Initiative actions. While the most attention has been focused on the \$1.7 billion authorized in Section 6071 of the DRA, the DRA had nineteen provisions in Title VI impacting the work of CMS's Elderly and Disabled Health Programs Group.

### **What is the MDS?**

The MDS is part of the federally-mandated Resident Assessment Instrument (RAI) which is the statutory name of the instrument that includes the MDS, Resident Assessment Protocols (RAPs), and the utilization guidelines. The MDS forms and manuals that detail the resident assessment process can be found and downloaded at the CMS website.<sup>8</sup> The MDS is the only national database collected on individual nursing home residents. By law, all residents in Medicare and/or Medicaid certified nursing homes must be assessed according to this prescribed process. CMS collects about ten million MDS records annually<sup>9</sup> on the approximately three million persons who use nursing homes each year.<sup>10</sup>

The standardized clinical information about residents, the national uniform collection methods, data availability, and its use in Medicare's skilled nursing facility prospective payment system (SNF PPS) and state case mix payment systems, have made the MDS a valuable source of information. Access to state and national level information from the MDS database is obtained through Data Use Agreements (DUAs). As of March 2006, there were 262 active DUAs for using MDS data.

Section Q of the MDS, one of its 18 sections, deals with Discharge Potential and Overall Status of the Resident, and has a potential use in identifying residents who might

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<sup>6</sup> CMS supported New Freedom Initiatives with three state Medicaid letters published on August 13, 2002, September 17, 2003), and August 17, 2004. The CMS state Medicaid director letters can be found at <http://www.cms.hhs.gov/SMDL/SMD/list.asp>

<sup>7</sup> See the CMS DEHPG FFY 2006 Annual Report at <http://www.cms.hhs.gov/NewFreedomInitiative/Downloads/DEHPG%20FY2006%20Annual%20Report.pdf>

<sup>8</sup> [http://www.cms.hhs.gov/NursingHomeQualityInits/20\\_NHQIMDS20.asp#TopOfPage](http://www.cms.hhs.gov/NursingHomeQualityInits/20_NHQIMDS20.asp#TopOfPage)

<sup>9</sup> Mor, V. (2004).

<sup>10</sup> Tucker, A.M. & Decker, F.H. (2004).

wish to leave the nursing home and live in the community.<sup>11</sup> Other sections of the MDS are also useful in providing information relevant to discharge planning, however only Section Q has three items to gauge discharge potential. The current wording of these items is shown below.

**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 1.Within 30 days 2.Within 31-90 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 supports, needs less restrictive care 2.Deteriorated-receives more support	

These Section Q questions implement federal regulations at 42 CFR 483.20 (b), which require the state’s Resident Assessment Instrument to include an assessment of discharge potential, and 42 CFR 483.20(k)(3)(ii)(1)(3) that requires, “A post-discharge plan of care that is developed with the participation of the resident and his or her family, which will assist the resident to adjust to his or her new living environment.”<sup>12</sup> Other Federal regulations at 42 CFR 483.12 discuss discharge planning from the standpoint of a resident’s rights should a nursing home wish to discharge a person. The language in 42 CFR 483.12 and 42 CFR 483.20 does not require a nursing facility to interview residents, determine their preferences, and actively help them to leave the home. The language neither describes nor proscribes what effective discharge planning is.<sup>13</sup>

<sup>11</sup> Illinois House of Representatives (2004, January) provides an example of this use of Section Q.

<sup>12</sup> See federal regulations at CFR 482.43 for hospital requirements for discharge planning.

<sup>13</sup> While this brief focuses on discharges to the community, planning regarding discharges to hospitals also needs to be improved since studies show hospitalizations of nursing home residents are frequently avoidable. See Gillick, M. & Steel, K. (1983); Gabow, P. et al. (1985); Saliba, D. et al. (2000); Intrator, O., Zinn, J. & Mor, V. (2004).

## Is the MDS Used Optimally to Support the New Freedom Initiative?

The single most consistent policy comment made by state staff about the MDS is that its Section Q, which deals with discharge planning, is not in step with CMS's New Freedom Initiative. Leslie Norwalk, the acting administrator of CMS in March, succinctly captured the essence of Olmstead and current CMS policy when she said:

“People want and deserve this freedom to choose care in the community. We know that when we give beneficiaries and their caregivers these opportunities, we get higher beneficiary satisfaction and better outcomes.”<sup>14</sup>

As currently designed, Section Q does not facilitate choice, dignity, and independence of nursing home residents. States and non-profit organizations attempt to use Section Q to help persons have a choice of long-term care services, but find it of limited utility given the current structure of the questions.

### The Isolation of Section Q

Within the MDS, Section Q is isolated. Section Q is one of the few sections in the MDS manual whose answers are not used in a RAP. Elements from Sections B through P are utilized in a RAP, but no elements from Q are used. Section Q is not used in any of the quality measures and quality indicators (QM/QIs) developed for use by CMS to guide institutional oversight surveys and for publication in “Nursing Home Compare.” “Nursing Home Compare” is a website run by CMS to educate consumers about their choice of long-term care facilities.<sup>15</sup> Section Q is not used in any of the resource utilization groups (RUGs) used to establish case mix payments for nursing homes. Finally, the section is not used in quarterly assessments. Section Q has the appearance of being an isolated section that is tacked on to the bottom of the assessment following the other sections.

### Answers to Section Q Items

What do the Section Q items tell us?

The CMS MDS Active Resident Information Report for the Third Quarter 2006 shows that **about 21% of the MDSs of residents nationally had a yes answer to item Q1a., “Resident expresses/indicates preference to return to the community.”**<sup>16</sup>

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<sup>14</sup> Norwalk, L. (2007, March). See

<http://www.cms.hhs.gov/apps/media/press/speech.asp?Counter=2084&intNumPerPage=10&checkDate=&checkKey=&srchType=&numDays=3500&srchOpt=0&srchData=&keywordType=All&chkNewsType=11&intPage=&showAll=&pYear=&year=&desc=&cboOrder=date>

<sup>15</sup> See

<http://www.medicare.gov/NHCompare/Include/DataSection/Questions/SearchCriteria.asp?version=default&browser=IE%7C6%7CWinXP&language=English&defaultstatus=0&pagelist=Home&CookiesEnabledStatus=True>

<sup>16</sup> Some state staff have expressed a concern with the CMS website information. The concern is that missing data are coded along with the “no” answers. However, the CMS website for Section Q reporting



About 17% of the MDS assessments reported the resident has a support person who is positive toward the discharge in response to Q1b.<sup>17</sup> For examples of similar state statistics see Ohio<sup>18</sup> and Alabama.<sup>19</sup>

### **Difficulties in Using the Answers**

States have difficulty using Section Q answers in a timely way. A frequently heard comment is that state managers are generally dissatisfied with the length of time it takes to get Section Q information from its database to transition workers. By the time the information gets to transition workers in nursing homes, the persons are no longer there, have lost key supports that would have been critical to successful transition, have experienced some adverse event, or have changed their mind. One state, Pennsylvania, has innovatively addressed this problem with a computer system called the Front Door Information System in which answers to Section Q items are transmitted to local agencies every two weeks.<sup>20</sup> An effective current use of Section Q is in the facility when the authorized Medicaid transition worker reads the MDS record to learn about potential Medicaid residents who can be helped to transition.

Despite these difficulties, advocates have urged states to use Section Q as a way of improving their discharge planning. The awareness of Section Q data has been spread among advocates in the aging and disability communities. The use of the internet has meant that one person or a small organization can develop sizeable mailing lists and send a mailing with the number of persons in each state that answered yes to Section Q questions.<sup>21</sup> Staff members in independent living councils are aware of Section Q. Two out of ten councils sponsoring nursing home transition program used Section Q in their work; others were aware of it but did not use it.<sup>22</sup>

A new version of the MDS is currently under development. CMS has a website where information regarding the status of this project can be found.<sup>23</sup> Appendix A shows

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indicates that this is not the case. See

<http://www.cms.hhs.gov/MDSPubQIandResRep/downloads/rdescript.pdf>

<sup>17</sup><http://www.cms.hhs.gov/MDSPubQIandResRep/>

<sup>18</sup> Ohio Department of Job and Family Services, Bureau of Long Term Care Facilities, Case Mix Section, (date unknown), p. 99.

<sup>19</sup> UAB Center for Aging, (2004, April 19), p. 31.

<sup>20</sup> The FDIS was created with the help of the state's nursing home reimbursement contractor who has access to the server containing MDS data. This solution to timely MDS access can be used by any of the other states that contract with the same national vendor. Pennsylvania also collects information on persons who are being transitioned and stores this in its OMNIA database.

<sup>21</sup> For an example, see Steve Gold's website <http://www.stevegoldada.com>

<sup>22</sup> Reinhard S. & Hendrickson L. (June 2006), p. 9. See also Davis v. CHHS C00-2532-SBA, (2003 December 12) Settlement Agreement Between Plaintiffs And Defendant City And County Of San Francisco, Section Q answers were used in a 2003 San Francisco case, *Davis v. CHHS*, C00-2532-SBA. The settlement agreement between the plaintiffs and the City and County of San Francisco required the city to set up a targeted case management program to do active discharge planning. The agreement stipulated that the plaintiffs would receive the first transition services and everyone who was "...identified in the MDS Section Q as having expressed a desire for discharge" would be one of the groups who were next in priority to receive discharge services.

<sup>23</sup> Center for Medicare & Medicaid Services,

[http://www.cms.hhs.gov/NursingHomeQualityInits/25\\_NHQIMDS30.asp#TopOfPage](http://www.cms.hhs.gov/NursingHomeQualityInits/25_NHQIMDS30.asp#TopOfPage)

the discharge item in the July 2006 Draft of MDS 3.0. CMS has been testing additional discharge-related items as part of its Staff Time and Resource Intensity Verification (STRIVE) study to refine the Medicare SNF payment system, RUG-III. Appendix A also shows the discharge items CMS is testing in the STRIVE study. The study is in progress in 240 facilities in 15 states and initial inter-rater reliability scores show some discharge items have lower than desirable scores. While it is positive that CMS is exploring alternative wording of section Q items, it is not clear whether other key components of MDS implementation (RAI manual, RAP, etc) are under consideration.

## **The Opportunities for Improvement**

Four potential improvements are recurrently discussed among State Medicaid Agency staff and other stakeholders involved in transition programs. If enacted, these improvements will help CMS place a higher priority on transition programs and the accompanying necessary discharge planning, improve discharge planning in the nation's nursing homes, and align the MDS with the New Freedom Initiative policies. The improvements are:

- Adding a 19<sup>th</sup> RAP for “Discharge Planning” that aids residents who express a preference for home or community based long-term care services
- Changing the MDS 2.0 User Manual
- Changing the wording of existing Section Q items in the MDS
- Adding Section Q to the Quarterly Assessment Form

### **Adding a 19<sup>th</sup> RAP for “Discharge Planning”**

#### **What is the Expectation of CMS regarding Discharge Planning?**

What does CMS expect an institution and the state to do in response to yes answers to Section Q? There is a prevailing view among the home and community-based community that the lack of follow-up and accountability for Section Q answers is a serious weakness in the MDS assessment and does not facilitate transition and discharge planning. The missing link is that no one is accountable for action based on the resident's response to Section Q and their preferences. The lack of accountability begs the question of “Why bother asking the questions if you do not do anything with the data?”

Observers have periodically suggested that CMS establish a 19<sup>th</sup> RAP for “Discharge Planning” in order to ensure a follow-up. There are currently 18 Resident Assessment Protocols (RAPs) as shown below.

**Table 1: Current Resident Assessment Protocols**

<b>Resident Assessment Protocols</b>
Delirium
Cognitive Loss / Dementia
Visual Function
Communication
Activities of Daily Living
Urinary Incontinence
Psychosocial Well Being
Mood State
Behavioral Symptoms
Activities
Falls
Nutritional Status
Feeding Tubes
Dehydration / Fluid Management
Dental Care
Pressure Ulcers
Psychotropic Drug Use
Physical Restraints

### **What is a RAP?**

A “RAP” is a resident assessment protocol. The main intent of the resident assessment process is to develop an individualized plan of care based on the identified needs, strengths and preferences of the nursing home resident. The current RAP format has three main parts and a summary review. The three parts are The Problem, The Triggers, and The Guidelines.

The Problem part defines the subject and describes why it is part of an assessment protocol. For example the first sentence in the Delirium RAP defines delirium. “Delirium (acute confusional state) is a common indicator or nonspecific symptom of a variety of acute treatable illnesses.” The Problem part of the RAP also goes on to describe its characteristics and provides guidance on how to treat it successfully.

The Trigger part is simply the list of those specific answers to MDS items that “trigger” the initiation of the RAP. The MDS is a preliminary screening instrument and if certain items are checked, then additional action is required of nursing home staff. For example, Section B is concerned with memory, cognitive skills and delirium and has one question on delirium with six sub questions in it. If any of six subquestions are answered with a 2, meaning a “new onset or worsening” of an existing condition, then a Delirium RAP is said to be “triggered.” The specific MDS items used to initiate follow-up action are the “triggers.” In this Delirium example, an answer of 2 to one of items B5a, B5b, B5c, B5d, B5e, B5f, or B6 would “trigger” the RAP.

The third part of the RAP, the Guidelines, is the most extensive. This Guidelines section covers the signs and symptoms used in a diagnosis and factors affecting the diagnosis such as medications, psychosocial history and present situation, moods, vision, dental, and other health conditions of the resident. For example, one of the Delirium guidelines is to check medications.

### **Why Should CMS Create a 19<sup>th</sup> RAP?**

Section Q is one of the few sections in the MDS manual whose answers are not used in a RAP. This is out of keeping with the intent of the MDS assessment process. Filling out the MDS is only the first step in the assessment model. As described in Chapter One of the User Manual, “all good problem identification models have similar steps.”<sup>24</sup> The first step is filling out the MDS, the second is the use of a decision making RAP followed by the development of a care plan, its implementation and then an evaluation of its results. The current treatment of discharge planning in the MDS abruptly truncates at the first step since there is currently no expectation for action or accountability for Section Q.

The creation of a 19<sup>th</sup> RAP, triggered by the resident’s preference for services outside the nursing home, is seen as a way of exploring discharge-related action on behalf of the interested resident. Such a RAP would emphasize the importance of discharge planning and provide the follow-up now missing in Section Q procedures. In a RAP of this nature, the role of the nursing home would be to support the resident’s preference. The absence of follow-up is seen as a weakness undermining the intent of Section Q, taking no action to support the resident’s preference, and is inconsistent with CFR and state licensing requirements for discharge planning.

In 1989, the Health Care Financing Administration (HCFA) funded the Nursing Home Case Mix and Quality (NHCMQ) demonstration to design and test a case mix-adjusted prospective payment system for Medicare and Medicaid. The MDS was developed under contract with the federal Medicaid program by researchers at the Research Triangle Institute, Brown University, the University of Michigan, and the Hebrew Rehabilitation Center for the Aged. One person who is familiar with these early efforts said that planning at the time envisioned two additional RAPs: one for pain management and the other for discharges, but that the two were never developed.<sup>25</sup>

### **Creating a RAP**

On the one hand, it is difficult to create a RAP since it means drafting guidelines, getting them reviewed, and having a serious look at what constitutes good discharge planning. On the other hand, staff who attended the March 2007 New Freedom Initiative point to the remarks of CMS Acting Administrator Leslie V. Norwalk<sup>26</sup> and their

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<sup>24</sup> Centers for Medicare and Medicaid Services. (2007, March), p. 1-1

<sup>25</sup> Personal communication with Kathy Wade of Myers and Stauffer, March 14, 2007.

<sup>26</sup> Norwalk, L. (2007, March). See

<http://www.cms.hhs.gov/apps/media/press/speech.asp?Counter=2084&intNumPerPage=10&checkDate=&checkKey=&srchType=&numDays=3500&srchOpt=0&srchData=&keywordType=All&chkNewsType=11&intPage=&showAll=&pYear=&year=&desc=&cboOrder=date>

continuing strong support for rebalancing long-term care, helping persons exercise their choice of long-term care, and building community programs. Adding a 19<sup>th</sup> RAP is seen as significant action that CMS can take to move the New Freedom Initiative. Changing the manual's instructions is easier and important to do but it is as not as significant an action as adding a RAP.

A RAP would not necessarily have to reiterate all acceptable discharge protocols but could further explore resident preference for discharge and resident perceptions about their own service needs. The work done in California on resident preference has been offered in whole or in part as the basis for a RAP.<sup>27</sup> The California Pathways preference interview takes from fifteen to twenty minutes to administer and document responses.<sup>28</sup> The assessment interview tool is attached in Appendix B of this report.

A RAP of this type would further assess preference to transition (stable preference), assess the resident's own perception about service need (feasibility), offer some minimal and generic information about services available in the community setting, and gather the resident's interest in further discussing discharge options and get permission to forward their name to a community-based referral agency for additional care planning and discharge planning.

## **Changing the MDS 2.0 User Manual**

The current MDS 2.0 user manual describes for each section the intent, definition, process, and coding of the items in the section as well as examples of their use. The current Intent of Section Q reads:

“To identify residents who are potential candidates for discharge within the next three months. Some residents will meet the “potential discharge” profile at admission; others will move into this status as they continue to improve during the first few months of residency.”

The Process text contains the following main paragraph:

“For new and recent admissions, ask the resident directly. The longer the resident lives at the facility, the tougher it is to ask about preferences to return to the community. After one year of residency, many persons feel settled into the new lifestyle at the facility. Creating unrealistic expectations for a resident can be cruel. Use careful judgment. Listen to what the resident brings up (e.g., Calls out “I want to go home”) Ask indirect questions that will give you better feel for the resident's preferences. For example, say “It's been about 1 year that we've known each other. How are things going for you here at (facility)?”

The text of the federal instruction is important because it is used as a guide for state instructions and subsequent federal language. For example, Maine's Training

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<sup>27</sup> California Pathways, Real Choice Systems Change Grant Preference Assessment Tool, (2005).

<sup>28</sup> Ibid.

Material for using the MDS repeats exactly the MDS 2.0 manual language.<sup>29</sup> Missouri's MDS manual repeats the MDS language but adds some direction regarding additional discharge assessments.

**“1. a.** Ask resident of plans directly if new admission. The longer a resident lives in a facility, the harder it is to ask about preferences. Use careful judgment here to avoid unrealistic expectations. This section provides data on discharge potential. Depending on resident's clinical status and circumstances, additional assessments to determine why the resident is not a candidate for discharge at this time and what care plan can be implemented to improve discharge potential may be warranted.”<sup>30</sup>

The manual used with the Staff Time and Resource Intensity Verification (STRIVE) study changes the description of the Intent to read “To identify residents who are potential candidates for discharge to the community.” This change eliminates the focus on 90 days and shorter stays. The next change the STRIVE manual contains is making the following sentence the first sentence in the Process comments: “The facility social worker should ask the resident these questions if the resident is able to respond.” The last change in the STRIVE manual is to end with Process comments: “If the resident cannot answer, contact the resident's family, significant others, or a legal guardian to answer on the resident's behalf questions XQ1a through XQ1e.”<sup>31</sup>

Specific suggestions for improving the User Manual instructions include:

- The tone and language need to be rewritten to place a more positive emphasis on discharge. The current language treats any mention of discharge as the raising of unrealistic expectation.
- Residents should be asked directly. The indirect questioning is not in keeping with the CMS emphasis on direct questions of the resident that is shown in the development work on the MDS 3.0.
- The manual and training protocols should instruct staff to take action to assist the resident to contact community resources as soon as a resident indicates a preference to return to the community.
- In the case of residents for whom a Q1a yes response is recorded but the Q1c indicates no plan to discharge, the MDS administrator should be required to contact the Ombudsmen or another state or county agency to ensure appropriate advocacy organizations have the referral.
- The manual should instruct MDS managers to work with community organizations, like local Independent Living Councils and Area Agencies on Aging, to develop a referral protocol for residents who indicate a preference to return to the community.
- The manual could instruct the nursing home worker to obtain the resident's permission to release their name to an agency that would provide additional information about home and community services.

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<sup>29</sup> The Maine Department of Health and Human Services, Bureau of Medical Services, (2004, July) p. 93

<sup>30</sup> Statewide Planning Committee for Improving MDS Assessment and Use, (2006, August). P. 32

<sup>31</sup> Iowa Foundation for Medical Care, (2006) p. 40

A belief that the MDS language is inconsistent with the New Freedom Initiative is shared by National Council on Disability which wrote in its 2003 Olmstead report:<sup>32</sup>

“This instrument [the MDS] is far too limited to serve as an accurate assessment of nursing facility residents’ potential to return to the community. It conditions discharge on expressed preference to return to the community... and on the attitudes of the person’s family and friends, and it suggests that long-term facility residents are less appropriate for discharge than others. This section of the instrument is inconsistent with *Olmstead* and should be revised to eliminate that inconsistency.”

Changing the user manual would be a substantial improvement to the MDS.

## **Changing the Wording of Existing Section Q items in the MDS**

### **Improvements to Item Q1a**

There is substantial discontent with the wording of Section Q. Discussions about improvements to Q1a focus on who is answering the item, who is asking the item, and what is done with the information. The current wording has unreliable results in part because Q1a is not a question. The MDS 2.0 instructions do not require the asker to actually ask the nursing home resident directly. Rather, item Q1a is a checkmark that the nursing home worker is supposed to fill out.

Indiana’s Nursing Facility Transition Manual takes into account that other people could be expressing a preference, rather than the resident’s preference, and describes the use of Section Q as follows:

“The response to Section Q during an MDS survey may be the response of the resident. The response may reflect the desires of the nursing facility or family members more closely than the desire of the resident. For this reason, Section Q is not to be considered as the sole indicator for transition interest, but rather as a starting place for the transition team in their transition candidate identification.”<sup>33</sup>

A nursing home social services employee will most likely fill out Section Q. State program staff tend to perceive social workers in nursing homes as having high turnover, working in an organizational atmosphere that does not encourage aggressive discharge planning, and lacking information about community resources and how to make effective pre-transition case planning.

Per federal regulations, only facilities with more than 120 beds are required to employ a qualified social worker on a full time basis.<sup>34</sup> The CMS Online Survey, Certification and Reporting database for December 2006 shows there were 15,885

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<sup>32</sup> National Council on Disability, (2003, September 29), p. 183

<sup>33</sup> Family and Social Services Administration, (2007, January 15) p. 20.

<sup>34</sup> 42 CFR 483.15 (g)(2)

nursing facilities with 1,719,114 beds for an average nursing home size of 108 beds.<sup>35</sup> The 2004 National Nursing Home Survey showed that 51.2% of facilities had fewer than 100 beds.<sup>36</sup> Thus the average-sized nursing facility in the United States is not required to have a social worker on staff. Many facilities employ “social services representatives” with little or no formal training.

These staff weaknesses are seen as compounding any problems that may exist with the wording of Section Q items. For example, preliminary findings in California investigating resident preference reveal 46% inconsistencies between the response to Q1a and resident responses to direct interview questions to the resident about discharge potential.<sup>37</sup>

### **Improvements to Item Q1b**

Item Q1b asks if the resident has “a support person who is positive towards discharge.” As currently worded, this item could be eliminated since it does not provide useful information. You can transition persons even if they do not have a support person and a no answer to the question might provide an excuse to the nursing home for not helping the person with transition assistance.

When discussed, persons usually say the question is vague. What if the answer is yes, what does that tell you? For example, what about the daughter who is positive towards discharge but lives 400 miles away?” Alternative wording can better identify what kind of support the person can provide. For example, “Resident has a support person who can help with discharge planning,” or, “Resident has a support person who will provide care after discharge.”

Another alternative wording might be to instruct the nursing home worker to collect the name and address of someone who can be contacted about the resident. For example, if Q1b is answered yes, then the name and contact information could be written on the MDS under the question. By keeping the contact information in the MDS, staff working with the resident would know where to look for it. The utility of this change is the more rapid identification of the resident’s informal supports as they are often essential to care planning.

### **Improvements to Item Q1c**

Interviews with state staff show it is not entirely clear what Item Q1c is used for.<sup>38</sup> Descriptions of transition programs do not mention or report on the use of answers to

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<sup>35</sup> OSCAR data is available from the Health Services Research and Evaluation group of the American Health Care Association. See <http://www.ahca.org/research/index.html>

<sup>36</sup> See <http://0-www.cdc.gov.mill1.sjlibrary.org/nchs/about/major/nnhsd/nnhschart.htm>, accessed May 29, 2007.

<sup>37</sup> Nishita, C. et. al., (2005, November).

<sup>38</sup> In fact, it has been excluded from analyses of discharge planning because of perceived limited utility. See Division of Health Care Policy and Research University of Colorado at Denver and Health Sciences Center (2006, September), p. 5.



Q1c.<sup>39</sup> None of the 18 RAPS use Q1c as a trigger or guideline. How useful is the information if the large majority of persons leave the home before 90 days? There is a new six-month stay requirement in the Deficit Reduction Act (DRA) Money Follows the Person Demonstration Grant language. Adding answers to the items that capture the possibility of longer than a 90-day stay--e.g. 90-120 day stay, 120-180 day stay, and more than 180 day stay--would make this item more useful to states' current activities.

### **Adding a Fourth Item to Section Q**

A fourth item could be added to strengthen discharge planning follow-up since discharge planning and care management are complicated and three items may not be sufficient.

Given the less than desirable reliability scores of items tested in STRIVE, in 2007 CMS staff considered testing an alternative wording for the current MDS 2.0 Q1a item. This alternative wording changed item Q1a to read "**May we provide your name to an agency that can assist you in learning about possible options for returning to the community.**" The CMS suggestion above "**May we provide your name...**", is a possible fourth item--a direct question that deals with the release of name issue and encourages the follow-up and communication necessary in discharge planning.

The question of obtaining permission from the resident has also been discussed in states where the Medicaid agency is reluctant to release personally identifiable information like the names of persons who answered yes to Q1a of the MDS. One possible solution that has been mentioned is to get the permission of the person to release their name. In practice, some state Medicaid agencies now release the names of Medicaid residents to contractors who perform administrative work for the state. Such contractors are considered agents of the state for the purpose of administering the Medicaid program and are obligated to protect the privacy of the Medicaid recipient. Other state Medicaid agencies have cited HIPAA concerns as reasons for not releasing names to the contractors performing nursing facility transition work for the state.<sup>40</sup>

### **Adding Section Q to the Quarterly Assessment Form**

CMS has created a multiple forms to collect MDS information. Currently, Section Q is part of the full initial assessment but is not asked on the quarterly assessment. If there is no significant change of condition (which triggers a full assessment), Section Q is not asked about until the next annual assessment after a resident is admitted. Advocates believe that discharge planning would be strengthened if items related to it were placed on the quarterly assessment. This would have a positive impact on quality of care because persons would not be unnecessarily institutionalized. Omitting discharge questions from the quarterly assessment implies that discharge

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<sup>39</sup> For example, Ribar, M. & O'Keeffe J., (2005, June).

<sup>40</sup> Reinhard S. & Hendrickson L. (June 2006) in their study of nursing facility transition projects found that "Comments about 'release of information' concerns were made by state staff and persons in non-profit agencies in four states" (p. 12).

planning is a secondary or less important activity that nursing home staffs don't really need to stress.

## **Conclusions**

There is a window of opportunity to change the MDS before the next version, MDS 3.0, is finalized. Not changing the MDS during this window will perpetuate a lack of emphasis on discharge planning, continue a long standing institutional bias in discharge planning, and be at cross purposes with current CMS policy. Discharge planning needs to be recognized as an important component of quality of care in nursing homes. Efforts to improve it encompass changing the MDS to better support the state and nursing home staffs that help residents exercise their choice of long-term care services.<sup>41</sup> As currently designed and administered, Section Q is not supportive of the choice, dignity, and independence of nursing home residents. Targeted changes to this section, changes in the instruction manual, quarterly assessment of discharge preferences, and creation of a 19<sup>th</sup> RAP are specific ways that public policy can better support consumers' desires to make informed choices about where they receive long-term services and supports.

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<sup>41</sup> See the Medicare Payment Advisory Commission report. Division of Health Care Policy and Research University of Colorado at Denver and Health Sciences Center (2006, September), p. 14.

## Appendix A: Preference Items in MDS version 3.0 and STRIVE

### The Discharge Item in the July 2006 Draft of MDS 3.0

CMS has been working on the next version of the Minimum Data Set MDS 3.0. Although an implementation date for MDS 3.0 has not been set, The CMS website currently says it is committed to completing the national evaluation by the end of 2007.<sup>42</sup> Section F (Preferences for Customary Routine, Activities, Community Setting) of the July 2006 draft version of the MDS 3.0 contained item F5, which is required to be completed only at admission. As shown below, the question is “Do you want to talk to someone about the possibility of returning to the Community?” No follow-up on a yes or no answer is required.

Section <b>F</b>		<b>Preferences for Customary Routine, Activities, Community Setting</b>		
<b>F5. Return to Community</b>				
↓ <b>Complete only on admission assessment</b> ↓				
Ask resident (or family or significant other if resident unable to respond):				
Enter	"Do you want to talk to someone about the possibility of <b>returning to the community</b> ?"			
<input type="checkbox"/>	0. <b>No</b>			
Code	1. <b>Yes</b>			
<b>F6. Skip Item: Staff Assessment Required</b>				
Enter	Was either F2, Preferred Routine Respondent, or F4, Activity Respondent coded 9?			
<input type="checkbox"/>	0. <b>No</b> → Skip to Section G, Functional Status			
Code	1. <b>Yes</b> → Complete F7, Staff Assessment of Activity and Daily Preferences			
<b>F7. Staff Assessment of Activity and Daily Preferences</b> —Complete only if unable to interview resident or other representative for either F1, Preferred Routine, or F3, Activity Pursuit Patterns.				
<b>Resident Prefers:</b>				
Check all that apply.	<input type="checkbox"/>	a. <b>Choosing clothes to wear</b>	<input type="checkbox"/>	k. <b>Place to lock personal belongings</b>
	<input type="checkbox"/>	b. <b>Caring for personal belongings</b>	<input type="checkbox"/>	l. <b>Reading books, newspapers, or magazines</b>
	<input type="checkbox"/>	c. <b>Receiving tub bath</b>	<input type="checkbox"/>	m. <b>Listening to music</b>
	<input type="checkbox"/>	d. <b>Receiving shower</b>	<input type="checkbox"/>	n. <b>Being around animals such as pets</b>
	<input type="checkbox"/>	e. <b>Receiving bed bath</b>	<input type="checkbox"/>	o. <b>Keeping up with the news</b>
	<input type="checkbox"/>	f. <b>Receiving sponge bath</b>	<input type="checkbox"/>	p. <b>Doing things with groups of people</b>
	<input type="checkbox"/>	g. <b>Snacks between meals</b>	<input type="checkbox"/>	q. <b>Participating in favorite activities</b>
	<input type="checkbox"/>	h. <b>Staying up past 8:00 p.m.</b>	<input type="checkbox"/>	r. <b>Spending time away from the nursing home</b>
	<input type="checkbox"/>	i. <b>Family or close friend involvement in care discussions</b>	<input type="checkbox"/>	s. <b>Spending time outdoors</b>
	<input type="checkbox"/>	j. <b>Use of phone in private</b>	<input type="checkbox"/>	t. <b>Participating in religious activities or practices</b>
			<input type="checkbox"/>	u. <b>None of the above</b>

<sup>42</sup> Centers for Medicare & Medicaid Services, (2007, July), DRAFT MINIMUM DATA SET, Version 3.0 (MDS 3.0) FOR NURSING HOME RESIDENT ASSESSMENT AND CARE SCREENING, retrieved on March 19, 2007 from <http://www.cms.hhs.gov/NursingHomeQualityInits/downloads/MDS30Draft.pdf>

In contrast to the existing four questions used in MDS 2.0, the July 2006 draft MDS 3.0 has only this single question. A possible reason for the elimination of three of the four discharge questions is the statement in the explanatory material for the July 2006 draft MDS that “To the extent possible, items that did not address screening for clinical symptoms and syndromes were eliminated. We have, however, retained items that currently form the basis for payment and quality measurement.”<sup>43</sup>

### **The Discharge Items used in the STRIVE Study**

However, CMS has also been testing additional discharge related items in its Staff Time and Resource Intensity Verification (STRIVE) study. The study is in progress in the states of Iowa and Kentucky. Studies in New York, Ohio, South Dakota and Texas are scheduled to begin in the early fall of 2007. Potential MDS items are being tested in 240 facilities in 15 states.

The STRIVE questions are shown below.

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<sup>43</sup> Centers for Medicare & Medicaid Services, (2007, July), DRAFT MINIMUM DATA SET, Version 3.0 (MDS 3.0) FOR NURSING HOME RESIDENT ASSESSMENT AND CARE SCREENING, p. i, retrieved on March 10, 2007 from <http://www.cms.hhs.gov/NursingHomeQualityInits>

## Appendix B: California Follow-up to Resident Preference Answers

SECTION XQ: DISCHARGE POTENTIAL AND INTEREST		
RESIDENT DISCHARGE INTERVIEW	<p style="text-align: center;">(This section should be completed by a social worker )</p> <p>Ask the resident (or responsible other, if needed).</p> <p>a. Would you like to learn about possible options for returning to live in the community, and if housing, services, and supports are available?</p>	
Code:	<p>0. No</p>	1. Yes
	<p>b. Do you have a place to live in the community?</p>	
Code	<p>0. No (skip to XQ1d)</p> <p>1. Yes (indicate all that apply, XQ1c)</p>	
	<p>c. Indicate all that apply</p>	
Code:	<p>0. No</p> <p>1. Own Home</p> <p>2. Home of relative or friend</p>	1. Yes
	<p>d. Where would you prefer to live in the community if housing and supports are available? (indicate all that apply)</p>	
Code:	<p>0. No</p> <p>1. Own Home</p> <p>2. Home of relative or friend</p> <p>3. Assisted living</p> <p>4. Board and Care (group home)</p> <p>5. Other</p>	1. Yes
	<p>e. Can we provide your name to an agency that can assist with giving you information about returning to the community (either the Aging and Disability Resource Centers (ADRC) or the Area Administration on Aging (AoA)</p>	
Code:	<p>0. No</p>	1. Yes

**INTERVIEWER NOTE:** The purpose of this interview is to determine an individual's preference for leaving the nursing home and to begin to identify services that might be needed to live in the community. However, many nursing home residents are not aware of living alternatives or the services that may be available to assist individuals living in the community. Thus, it is essential to ensure that individuals who respond that they do not want to leave the nursing home are fully informed when making this decision. In this regard, the questions that list services that people might need (questions 3-22) are not used to screen people from further consideration for relocation but to educate them about services that might be available.

**MFP Preference Interview Data Collection Tool**

**Short Version – 1-6-05**

Subject ID #: \_\_\_\_\_ Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

Interviewer ID #: \_\_\_\_\_ Start Time: \_\_\_\_\_

*Hi I'm \_\_\_\_\_ (INSERT YOUR NAME) from the University of California, Los Angeles. I am interviewing MediCal nursing home residents here at the \_\_\_\_\_ (NAME OF NURSING HOME) as part of a study paid for by the California State Department of Health and Rehabilitation. This project involves helping people who live in nursing homes move into the community to live in other places, which can range from an assisted living facility or a group housing arrangement to homes or apartments using the same money that is spent for nursing home care. I'd like to ask you some questions about alternatives to living in a nursing home and where you (your relative) might want to live. We are asking all MediCal nursing home residents or their family at this facility these same questions. We do not know who might be able to move out of the nursing home, and we cannot promise that you (your relative) would be moved out of the nursing home. We don't want to create false hope about moving. But there are other choices for where a person might live with the proper resources and supports. This interview will take 10 minutes. Is now a good time and can I ask you some questions?*

\_\_\_\_\_ NO, **STOP**  
**INTERVIEW**  
 \_\_\_\_\_ YES, **CONTINUE**

1. Would you (your relative) **want** to live somewhere other than the nursing home?  
 \_\_\_\_\_ NO (Go to Q1a & 1b) \_\_\_\_\_ Don't know (Go to Q1b) \_\_\_\_\_ YES  
 (Go to Q2)

1a. What are some reasons you (your relative) want to continue living in the nursing home? (LIST)

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

1b. There are options for living outside the nursing home. You could live in your own home or apartment with help; you could live in an assisted living facility or you could live in a group home with 3 to 6 other people and share services and help. Would any of these options/choices make you change your mind about leave the nursing home?

\_\_\_\_\_ NO, (Go to Q1c)

\_\_\_\_\_ YES, (Go to Q2)

1c. I am going to list some services that you might be able to get. Listen to them and tell me if you need them. Later I'm going to ask if getting these services would change your mind about leaving the nursing home. (Go to Q3)

2. Where would you live and with whom?

\_\_\_\_\_Apartment or home alone

\_\_\_\_\_Apartment or home with family

\_\_\_\_\_Apartment or home with spouse or partner

\_\_\_\_\_Assisted living facility

\_\_\_\_\_Group home

\_\_\_\_\_No place to go

a. \_\_\_\_\_Are you willing to live in a group home with 3 to 6 other people?

b. \_\_\_\_\_Are you willing to live in an assisted living facility?

Now I'm going to list the services that might help you live outside the nursing home. Listen to them and tell me if you need the service.

3. Help getting out of bed and into a chair?

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

4. Help getting started to eat? For example, cutting up your food, or getting your silverware at meal times?

- \_\_\_\_\_ NO,  
\_\_\_\_\_ YES,
5. Help eating? For example, someone to feed you?  
\_\_\_\_\_ NO,  
\_\_\_\_\_ YES,
6. Help turning or moving in bed?  
\_\_\_\_\_ NO,  
\_\_\_\_\_ YES,
7. Help getting to the toilet?  
\_\_\_\_\_ NO,  
\_\_\_\_\_ YES,  
\_\_\_\_\_ Wears adult briefs or pads
- a. Help changing your adult brief or pad?  
\_\_\_\_\_ NO,  
\_\_\_\_\_ YES,
8. About how many times during the day do you think you need help getting to the toilet  
OR changing your adult brief/pad? \_\_\_\_\_
9. Help with morning care like brushing your teeth, washing your face, brushing your hair,  
or putting on your deodorant?  
\_\_\_\_\_ NO,  
\_\_\_\_\_ YES,
10. Help with bathing or taking a shower?  
\_\_\_\_\_ NO,  
\_\_\_\_\_ YES,
11. Help walking inside?  
\_\_\_\_\_ NO,  
\_\_\_\_\_ YES,
12. Help walking outside?  
\_\_\_\_\_ NO,  
\_\_\_\_\_ YES,
13. What kind of help do you need?  
\_\_\_\_\_ Cane  
\_\_\_\_\_ Walker  
\_\_\_\_\_ Safety rails on walls  
\_\_\_\_\_ Wheelchair



a. If Wheelchair, do you need help getting around in your wheelchair  
**inside?**

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

b. If Wheelchair, do you need help getting around in your wheelchair  
**outside?**

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

14. Help getting dressed in the morning?

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

a. If YES, what do you need help with

\_\_\_\_\_Shoes/socks

\_\_\_\_\_Shirt/dress

\_\_\_\_\_Pants

15. Help getting undressed at night?

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

a. If YES, what do you need help with

\_\_\_\_\_Shoes/socks

\_\_\_\_\_Shirt/dress

\_\_\_\_\_Pants

16. Help using the telephone?

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

a. YES, Do you need

\_\_\_\_\_Volume increased, can't hear

\_\_\_\_\_Large numbers, can't see to dial

\_\_\_\_\_Dialing assistance, can't dial

17. Help cooking or preparing your meals?

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

18. Help with medications?

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

19. Help with housework?

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

a. If YES, what do you need help with

\_\_\_\_\_ Laundry

\_\_\_\_\_ Washing dishes

\_\_\_\_\_ Cleaning house

20. Help shopping?

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

21. Help with transportation?

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

22. Help managing your money or finances?

\_\_\_\_\_ NO,

\_\_\_\_\_ YES,

a. If YES, do you need help with

\_\_\_\_\_ Paying your bills

\_\_\_\_\_ Balancing your check book

\_\_\_\_\_ Tracking your bank accounts

23. *If resident/proxy responded "NO" to initial preference to leave nursing home, If you had help available for any of these services, would you change your mind about leaving the nursing home?*

\_\_\_\_\_ NO, STOP INTERVIEW

\_\_\_\_\_ YES,

a. If YES, Where would you live and with whom?

\_\_\_\_\_ Apartment or home alone

\_\_\_\_\_ Apartment or home with family

\_\_\_\_\_ Apartment or home with spouse or partner

\_\_\_\_\_ Assisted living facility

\_\_\_\_\_ Group home

\_\_\_\_\_ No place to go

b. \_\_\_\_\_ Are you willing to live in a group home with 3 to 6 other people?

c. \_\_\_\_\_ Are you willing to live in an assisted living facility?

Thank you so much for taking the time to answer these questions. We want to be sure you understand that answering these questions does **NOT** mean that you will be relocated out of the nursing home. We don't want to create false hope about moving. We are only getting information on nursing home residents who would prefer to live some place other than the nursing home.

OFFER FOLLOW UP WITH OMBUDSMAN INTERVIEW, INDEPENDENT LIVING CENTER, AND/OR RESEARCHER.

**STOP INTERVIEW, GET HIPAA CONSENT SIGNED (TELL FAMILY MEMBERS THIS WILL BE MAILED TO THEM)**

24. How clear is the person in terms of what services are needed?

- \_\_\_\_\_ 1-Not at all clear
- \_\_\_\_\_ 2-Somewhat clear
- \_\_\_\_\_ 3-Neither clear nor unclear
- \_\_\_\_\_ 4-Somewhat clear
- \_\_\_\_\_ 5-*Very clear*

25. How motivated is the person to relocate?

- \_\_\_\_\_ 1-Not at all motivated
- \_\_\_\_\_ 2-Somewhat unmotivated
- \_\_\_\_\_ 3-Neither motivated nor unmotivated
- \_\_\_\_\_ 4-Somewhat motivated
- \_\_\_\_\_ 5-Very motivated

*End Time:* \_\_\_\_\_



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