GUIDANCE AND RESOURCES FOR LONG TERM CARE FACILITIES: USING THE MINIMUM DATA SET TO FACILITATE OPPORTUNITIES TO LIVE IN THE MOST INTEGRATED SETTING

U.S. Department of Health and Human Services, Office for Civil Rights
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The U.S. Department of Health and Human Services' Office for Civil Rights (OCR) is issuing this guidance to help long term care facilities comply with their civil rights obligations by administering the Minimum Data Set (MDS) appropriately so that their residents receive services in the most integrated setting appropriate to their needs. Failure to properly administer the MDS places a facility's Medicaid and Medicare reimbursements in jeopardy.[1] Furthermore, inadequate administration of the MDS threatens the state and administrative agencies' compliance with civil rights laws. The state and state administrative agencies must provide services to residents in the most integrated setting. The unnecessary placement of a resident in a long term care facility may constitute discrimination under Section 504 of the Rehabilitation Act (Section 504) and Title II of the Americans with Disabilities Act, as interpreted by the U.S. Supreme Court in *Olmstead v. L.C.*[2]

OCR is responsible for enforcing Section 504 of the Rehabilitation Act as it applies to entities that receive HHS Federal financial assistance. Long term care facilities receive Federal financial assistance by participating in programs such as Medicare and Medicaid. Section 504 prohibits discrimination based on disability, including the unnecessary segregation of persons with disabilities. Unjustified segregation can include continued placement in an inpatient facility when the resident could live in a more integrated setting. This concept was set forth in the *Olmstead* decision which interpreted the same requirements in the Americans with Disabilities Act.

The MDS, a mandated quarterly assessment administered to all nursing home residents, has questions that can connect long term care residents with opportunities to live in the most integrated setting and assist the state in meeting its non-discrimination requirements under Section 504 and the Americans with Disabilities Act. Specifically, Section Q of the MDS provides a process that, if followed correctly, gives the resident a direct voice in expressing preference and gives the facility means to assist residents in locating and transitioning to the most integrated setting.

OCR has found that many long term care facilities are misinterpreting the requirements of Section Q of the MDS. This misinterpretation can prevent residents from learning about opportunities to transition from the facility into the most integrated setting. We are therefore providing a series of recommendations for steps that facilities can take to ensure

[1] See 42 CFR 483.1(b); 42 C.F.R. 483.20(b)(1)(xvi); and 42 C.F.R. 483.20(g)
[2] *Olmstead v. L.C.*, 527 U.S. 581 (1999).

Section Q of the MDS is properly used to facilitate the state's compliance with Section 504 and to avoid discrimination.

1. **Strong Relationships with the Local Contact Agency can Help Long Term Care Facilities Understand the Availability of Community Based Services**

All long term care facilities should know their Local Contact Agency and have a working relationship with it. A Local Contact Agency is a local community organization responsible for providing counseling to nursing facility residents on community support options. Long term care facilities must make referrals to the Local Contact Agency whenever a resident would like more information about community living or alternative living situations to the facility. If you do not have contact information for the Local Contact Agency, you should contact the State Point of Contact found at www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/community-living/downloads/state-by-state-poc-list.pdf.

When the long term care facility makes a referral to a Local Contact Agency, OCR recommends that a facility representative serve as a liaison to the Local Contact Agency staff member and maintain regular communication with the Local Contact Agency regarding the resident. The Facility must in no way impede the assessment, planning, and transitioning process triggered by the referral to a Local Contact Agency.

Facility staff members should work with the Local Contact Agency to incorporate the Local Contact Agency's Transition Plans for the resident into the resident's facility discharge plan and active care plan.

OCR also recommends that the facility invite the Local Contact Agency to provide seminars/presentations to residents and staff on a regular basis (*e.g.*, every six months), about the services it provides, community-based settings in which residents can choose to receive services, and the residents' opportunity to seek a referral regarding potential transition to the community.

2. **Proper Administration of MDS Section Q, Questions, Q0400, Q0500, and Q0600 is Critical in Assisting Residents to Receive Services in the Most Integrated Setting**

The goal of Section Q of the MDS is to "ensure that all individuals have the opportunity to learn about home and community based services and have an opportunity to receive long term care in the least restrictive setting possible."[3] Because Section Q is designed to assist residents in returning to the community or another more integrated setting appropriate to their needs, proper administration of Section Q of the MDS can further a state's compliance with civil rights laws.

[3] Resident Assessment Instrument (RAI) Manual at Q-14.

a. MDS Section Q, Q0400: Is active discharge planning already occurring for the resident to return to the community?[4]

OCR found in a survey of long term care facilities that many facilities misunderstand this question. If active discharge planning is not occurring, then the facility must ask the resident the follow up question "Do you want to talk to someone about the possibility of leaving this facility and returning to live and receive services in the community?" [5] Most facilities responding believe that they do not have to ask residents this question if the resident has a "discharge plan." However, the MDS process requires these individuals to be in ***active*** discharge planning, and it appears that some residents have a discharge plan that was created as a matter of course and not as part of an active transition process.

An ***active*** discharge plan means a plan that is being currently implemented. In other words, the resident's care plan has current goals to make specific arrangements for discharge, staff are taking active steps to accomplish discharge[6], and there is a target discharge date for the near future. If there is not an ***active*** discharge plan, residents should be asked if they want to talk to someone about community living and then referred to the Local Contact Agency accordingly. Furthermore, referrals to the Local Contact Agency are recommended as part of many residents' discharge plans.[7] Such referrals are a helpful source of information for residents and facilities in informing the discharge planning process.

OCR recommends that facilities continue to use the most current MDS assessment tool and answer MDS question Q0400 ("Is Active Discharge Planning already occurring for the Resident to Return to the Community?") "no" for all residents of the facility unless a referral to the Local Contact Agency occurred and the Local Contact Agency has met with the resident. MDS Question Q0400 should only be answered "yes" for permitted reasons, such as:

- The resident is currently being assessed for transition by the Local Contact Agency;
- The resident has a Transition Plan[8] in place, which has all of the required elements and has been incorporated into the resident's Discharge Plan; or,

[4] RAI Manual at Q-8.
[5] RAI Manual at Q-14.
[6] The MDS manual states that discharge instructions should include items such as, but not limited to: arrangements for durable medical equipment, arrangements for housing. and arrangement for transportation to follow-up appointments. *See* RAI Manual at Q-9.
[7] RAI Manual at Q-9.
[8] The term "Transition Plan" here means documentation completed and maintained by members of a Local Contact Agency pertaining to a particular resident of the facility, that identifies the direction for the care and services the resident needs to live in the most integrated setting, including the provision of necessary care and services to the resident in the most integrated setting and all other arrangements necessary to allow the resident to live in the most integrated setting.

- The resident has an expected discharge date of three (3) months or less[9], has a discharge plan in place with all the required elements, and the discharge plan could not be improved upon with a referral to the Local Contact Agency.

If the response to MDS question Q0400 is "no" (i.e., the resident does not have an active discharge plan in place), facilities should ask the resident MDS question Q0500, "Do you want to talk to someone about the possibility of leaving this facility and returning to live and receive services in the community?" Any resident who answers "yes" to Q0500 must be referred to the Local Contact Agency.

b. MDS Section Q, Q0500: Do you want to talk to someone about the possibility of leaving this facility and returning to live and receive services in the community?[10]

Another example of facilities misunderstanding Section Q includes confusion regarding the administration of Q0500. Most facilities never ask, or nearly never ask, Q0500 because they believe they do not need to ask the question because all residents have discharge plans in place. However, unless the resident has an ***active*** discharge plan, the resident must be asked Q0500.[11] If a resident answers "yes" to this question, a referral to the Local Contact Agency is required[12] and the Local Contact Agency will establish contact with the resident to discuss the availability of appropriate services in the community. When asking question Q0500, the RAI manual instructs nursing home staff to convey to residents that this question is intended to "provide the opportunity for the resident to get information and explore the possibility of different settings for receiving ongoing care."[13] In other words, the resident should be encouraged to learn about possibilities by talking to the Local Contact Agency. Most residents do not know what alternatives to inpatient care may exist, so the word "possibility" in the question is essential. It is important for facilities to provide the residents a clear context as to the purpose of Q0500. Failing to provide context for the question could result in residents remaining in institutions longer than necessary.

c. MDS Section Q, Q0600: Has a referral been made to the Local Contact Agency?[14]

Residents who express interest in learning about living outside of the facility, either through answering affirmatively to question Q0500 or expressing an interest to direct

[9] The RAI Manual does not set a time frame for coding this item "yes"; however, OCR believes this timeframe is appropriate and should be considered a best practice concerning facilities' civil rights obligations.
[10] RAI Manual at Q-10.
[11] Unless the resident specifically requests to not be asked this question in their quarterly assessment. However, annual comprehensive assessments must ask Q0500. See MDS Q0490 at RAI Manual Q-12.
[12] RAI Manual at Q-16.
[13] RAI Manual at Q-15.
[14] RAI Manual at Q-20.

care staff[15] at other times, should be referred to the appropriate Local Contact Agency for assistance, including education on the process of obtaining community placement and any other appropriate services. Once any facility staff learns of the resident's interest, a referral to the Local Contact Agency must be made in a reasonable amount of time.[16] Furthermore, it is recommended that the referral be documented in the resident's Discharge Plan.

Facilities must recognize that residents can make a free choice about where to receive services and cannot be pressured to remain in the facility. Facilities must not deny residents a referral to the Local Contact agency for inappropriate reasons, including but not limited to:

- The facility inserts its judgment and overrides the resident's expressed interest based on factors such as a belief that the resident's disability is too severe to transition;
- A belief that discharge is not possible because the resident has no home or support in the community, or a previous transition was not successful; and/or
- The family or caregiver does not want the resident to move.

The only reason a facility may refrain from making a referral to the Local Contact Agency when requested by the resident is when the resident has an *active* discharge plan.[17]

3. The Facility Should Update its Policies and Procedures to Comply with this Guidance Document and Provide Periodic Training.

OCR recommends that facilities review and revise existing policies and procedures or develop new policies and procedures on: (1) discharge planning; (2) MDS administration, and; (3) the Local Contact Agency referral processes. The policies and procedures should comply with this guidance document, and the facility's practices must be consistent with this guidance.

In addition, OCR recommends that each facility train all staff involved in conducting, reviewing, assessing, implementing, or otherwise utilizing the MDS assessment (including direct care staff, care teams, the facility's senior management team members, and workforce members in any other relevant position) on Section Q of the MDS. OCR recommends using the State Resident Assessment Instrument Coordinator (RAI), who is responsible for coordinating MDS training in the State, or a trainer recommended by the RAI, to conduct the training on the MDS.

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[15] Direct care staff are the facilities' workforce members who personally interact with residents while providing health care or similar support services.

[16] RAI Manual at Q-16. The manual recommends ten business days as a "reasonable" amount of time to make this referral.

[17] See section 2. a. of this guidance document.

OCR also recommends that each facility train all staff, including direct care staff and Care Teams, the Facility's senior management members, and work force members in any other relevant position on:

- the Local Contact Agencies which serve the facility's geographic areas;
- the services the Local Contact Agencies provide and the role they play in assisting individuals interested in living in a community setting;
- when and how to contact the Local Contact Agency;
- how to work collaboratively with the Local Contact Agency for the benefit of residents of the facility; and
- home and community-based services provided by state agencies.

OCR recommends that individuals from outside the facility with extensive knowledge of the services and role of the Local Contact Agencies and the state home and community-based service systems provide the training. For example, Aging and Disability Resource Center (ADRC) staff, local center for independent living (CIL), Area Agency on Aging (AAA), or another agency that is familiar with transitioning residents to the community, may be able to train staff on these five issues. Furthermore, to fulfill these training recommendations, contact can be made with the State Point of Contact for MDS 3.0 Section Q Referrals for suggestions on trainers who have the recommended knowledge.[18]

4. Further Resources

For more information on the administration of the MDS and technical assistance please visit the following links:

- MDS 3.0 Technical Information at: www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/NHQIMDS30TechnicalInformation.html

- State Operations Manual (SOM) at: www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Internet-Only-Manuals-IOMs-Items/CMS1201984.html

- MDS 3.0 RAI Manual at: www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/MDS30RAIManual.html

- MDS 3.0 Training at: www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/NHQIMDS30TrainingMaterials.html

- Skilled Nursing Facilities Long-Term Care Open Door Forum at: www.cms.gov/Outreach-and-Education/Outreach/OpenDoorForums/ODF_SNFLTC.html

[18] See www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/community-living/downloads/state-by-state-poc-list.pdf.