



Center for Medicaid and State Operations

Ref: S&C-05-19

DATE: February 18, 2005

TO: State Medicaid Agency Directors

FROM: Director
Survey and Certification Group

Director
Disabled and Elderly Health Programs Group

SUBJECT: Release of Long Term Care Minimum Data Set (LTC/MDS) Data to State Medicaid Agencies, Section 1915 Waiver Programs, and “Real Choice Systems Change Grant” Programs in Order to Assist States’ Title II, Americans with Disabilities Act (ADA) Compliance Activities.

Letter Summary

- This letter provides guidance on CMS disclosure of LTC/MDS data to State Medicaid Agencies, Section 1915 Waiver Programs, and “Real Choice Systems Change Grant” Programs in order to assist states in their efforts to comply with the integrated care setting and reasonable accommodation requirements of Title II of the ADA.
- This letter should be shared with appropriate state agency staff and designated entities that are working on waiver and grant programs.

Background

The Centers for Medicare & Medicaid Services (CMS) and its state partners have made important strides in identifying and eliminating barriers to community living. Many states are developing and implementing service delivery, financing, and administrative mechanisms to prevent and correct inappropriate placement of individuals in institutions and ensure adequate community supports. By allowing states access to LTC/MDS data, State Medicaid Agencies, Section 1915 Waiver programs, and Real Choice Systems Change Grant Programs can identify and transition LTC residents who would like to, and could appropriately be placed in the community. These ADA requirements have been clarified by the Supreme Court in Olmstead v. L.C., 527 U.S. 581 (1999). For a more detailed discussion of how states might utilize LTC/MDS data to further their Olmstead and ADA programs, please find “In Brief.....Using the Minimum Data Set to Facilitate Nursing Home Transition” available at www.communitylivingta.info. This site is funded via a Real Choice Systems Change Grant from CMS to the Community Living Exchange Collaborative. The purpose of this grant is to provide technical assistance to grantees, including facilitating the sharing of information across states. This site is administered by Boston College on behalf of the Community Living Exchange Collaborative.

Data collected through the LTC/MDS is maintained by CMS in accordance with the Privacy Act of 1974. The Privacy Act limits the disclosure of individually-identifiable information held by Federal agencies and permits disclosure of such information only when the purpose of the disclosure is one of the bases for the data collection's establishment, and for specific "routine uses." These "routine uses" are listed in a published (via the Federal Register) System of Records Notice. Routine uses include various purposes such as administration of the Survey and Certification Program, and payment of LTC services, which include skilled nursing facilities (SNFs), nursing facilities (NFs), SNF/NFs, and hospital swing beds, and to study the effectiveness and quality of care provided in those facilities.

Under the Privacy Act provisions, states and/or CMS are required to track disclosures of LTC/MDS data at the beneficiary level. LTC/MDS data releases may be tracked by the state or by CMS.

Use of MDS Data for Compliance with Title II Requirements

If the conditions discussed in this letter are met by the execution of a data use agreement (DUA), CMS will provide State Medicaid Agencies with LTC/MDS data on the residents of that state and beneficiaries of that State's Medicaid program. One purpose of such use is to assist states in their efforts to comply with the integrated care setting and reasonable accommodation requirements of Title II of the ADA. CMS believes that the LTC/MDS data will help states and designated entities identify residents with disabilities who have a desire to live in the community, and will provide information related to the level of services necessary to fulfill states' ADA requirements in relation to such individuals.

In an effort to further assist states in ADA compliance activities, CMS has developed a report providing aggregated current resident responses to the LTC/MDS Section Q1a. The report provides state, and more importantly, county level information on resident responses. This data is available on the CMS Web site at <http://www.qtso.com/mdsdownload.html> and is updated quarterly.

Obtaining MDS Data

CMS will allow State Medicaid Agencies or designated entities access to LTC/MDS data on the residents and Medicaid beneficiaries of that state after it receives and approves a Medicaid Data Use Agreement (MDUA) from the state. The MDUA must be signed by the requestor and the custodian of the data and binds the parties to the requirements of the Privacy Act and the applicable LTC/MDS System of Records. CMS has prepared the updated MDUA with ADA provisions and revised the Addendum sheet to include Title II ADA activities. The required forms and other information can be accessed at www.cms.hhs.gov/privacyact/requests.

Completed MDUAs should be submitted to the Regional Office MDS representative for review and approval. States that execute a new or updated MDUA may obtain all state-specific LTC/MDS data for purposes listed in #6 of the MDUA, which include activities aimed at ensuring state compliance with the requirements set forth in Title II of the ADA.

States that request the LTC/MDS data for purposes outside those specified in the MDUA must request a Standard DUA. The Standard DUA is an open-ended agreement that allows the requestor to request LTC/MDS data for other uses. Those uses are also subject to the limitations on use and disclosure of individually identifiable information held in the LTC/MDS System of Records.

States that have already submitted a MDUA for access to the LTC/MDS data may update those agreements to allow for the use of LTC/MDS data in ADA compliance programs. States should complete the Addendum sheet to reflect the custodian's information, signature, and additional use for ADA purposes.

State Medicaid Agencies with new or updated MDUAs and tracking mechanisms may obtain all state-specific LTC/MDS data. States that require assistance with the extraction of data will be charged a fee for each year of MDS data requested.

Technical Assistance

States that have not executed an MDUA and require technical assistance to establish how to comply with tracking requirements may contact Karen Edrington of CMS' Division of National Systems at 410-786-2166 or by email at kedrington@cms.hhs.gov.

/s/
Thomas E. Hamilton

/s/
Gale Arden