JudyAnn Bigby, M.D., Secretary  
Executive Office of Health and Human Services  
One Ashburton Place, Room 1109  
Boston, Massachusetts 02108

Dear Dr. Bigby:

This letter is a request for additional information necessary for the Centers for Medicare & Medicaid Services (CMS) to evaluate the home and community-based services (HCBS) waiver programs that provide services to individuals aged 18 years and older with mental retardation (CMS control numbers MA-0826.R00, MA-0827.R00, MA-0828.R00). Thank you for the documentation provided to date by the Office of Medicaid. We have enclosed a list of questions for which we require supplementary information and data.

We have recently learned details about aversive interventions and deprivation procedures imposed on children and adults who may be enrolled in these Medicaid waiver programs or who may be receiving services reimbursed with Medicaid funding through the Department of Developmental Services and/or local education authorities. Although the information in this letter refers specifically to a particular service provider, this request for additional information encompasses any and all providers that impose aversive procedures and receive reimbursement that includes Medicaid funds.

A provider of residential habilitation services, the Judge Rotenberg Center in Canton, has been the subject of numerous news articles in the public media. The information we have seen includes a deeply disturbing report issued by the New York State Education Department several years ago (Accessible at http://boston.com/news/daily/15/school_report.pdf). In addition, a more recent article indicates that the Judge Rotenberg Center is under investigation by the U.S. Department of Justice, Civil Rights Division (See the news article at http://www.disabilityrightsoregon.org/news/doj-initiates-official-investigation-of-the-judge-rotenberg-center-jrc).

This information raises serious concerns about whether the State’s implementation of these waiver programs demonstrates substantial compliance with the Federal HCBS waiver assurances, including the assurance that the State implements an effective system to protect the health and welfare of HCBS waiver participants. Published descriptions of aversive interventions and deprivation procedures provide a picture of residential settings which cannot be characterized as
“home-like.” Aversive and intrusive interventions reportedly include repeated and painful electric shock, potentially unnecessary restraint and seclusion, and meal deprivation. Questions have also been raised about the adequacy of staff training.

In view of the information we have received as well as our understanding that State regulations (See 115 CMR chapter 5) permit certain aversive intervention and deprivation procedures to be imposed on people with developmental disabilities and autism, we request additional information about the State’s oversight and monitoring of Medicaid participants in HCBS waivers. While the regulation of residential facilities rests with State and local authorities, CMS’s oversight of home and community-based waiver services includes oversight of the States’ implementation of systems of quality monitoring for services provided in these settings and reimbursed with Medicaid Federal matching funds.

This request includes but is not limited to the three waivers we are currently reviewing to determine whether the State substantially meets the six HCBS waiver assurances described in Federal regulations at 42 CFR 441.302. We would also appreciate information concerning other Medicaid eligible children and adults receiving Medicaid-funded services, and potentially subject to aversive procedures, from the same providers.

Please respond in writing to this request within 30 days of your receipt of this letter. After reviewing the requested additional information, CMS staff will contact your staff to discuss necessary follow up activities. Please call Nancy Grano at (617) 565-1695 with any questions related to this request.

Sincerely,

/s/

Richard R. McGreal
Associate Regional Administrator

Enclosure

cc:
Dr. Julian Harris
1. Describe the State’s processes to ensure that the UMMS (University of Massachusetts Medical School) quality data is accurate. Include specific information regarding the validity of UMMS sampling methodology when less than 100 percent of waiver participants or providers are reviewed with regard to performance measures and outcomes. Include sample summary data from State agency’s activities to validate UMMS quality reports.

2. The State reported that State surveyors review providers as part of the licensure and certification process and review a sample of individuals served who have behavioral plans or restrictive interventions in place. Outcomes for this performance measurement of appropriate safeguards for restrictive interventions were reported at 74 percent and 77 percent for waiver years one and two, respectively. Of the providers reviewed, 38 providers used restrictive practices in waiver year one, and 22 used these practices in waiver year two. Of the 38 in year one, 28 had appropriate safeguards in place. Of the 22 providers in year two, 17 had appropriate safeguards in place. Describe further the findings for this performance measure and the remediation efforts taken by the State to address any deficiencies.

3. With regard to the use of aversive interventions characterized by the State as level two and level three interventions, list all HCBS waivers whose participants could be subject to these procedures. Are additional Medicaid beneficiaries who are receiving State plan services such as habilitation also subject to these procedures? Provide a full description of the scope of this treatment on Medicaid eligible individuals.

4. Please provide detailed census and expenditure data on Medicaid eligible residents for all residential providers that are permitted to use aversive interventions described in 115 CMR chapter 5 as level two and three interventions. This information must include the following detail, stratified by provider and by age group (age 0-20, ages 21-64, 65 and older); home State (Massachusetts or other State, if placed by family or home State agency); total number of residential facilities; unduplicated number of residents, further stratified by section 1915(c) HCBS waiver participation, if any; total Medicaid payments (whether made directly to the provider by MassHealth, DDS or other entities such as local education authorities, for example, for school-based services). (Sample chart below)

<table>
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<th># res facilities</th>
<th>Age Group</th>
<th>Home State</th>
<th>1915(c)</th>
<th>Undup Count</th>
<th>Total Medicaid Payment</th>
<th>Other public payment source of Medicaid funding</th>
<th>Total other public payment</th>
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<tr>
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</tbody>
</table>
5. Submit the most recent licensing and certification reports, State and Federal foster care reports, Department of Education reports, summary reports of incidents and complaints, restraint summary reports and mortality reporting data, including data regarding the Judge Rotenberg Center and other residential providers that are permitted to use aversive procedures on Medicaid eligible individuals. The information should include the most recent provider reports by the Department of Developmental Services from its Annual Standard Quality Review Process. Information should include summary reporting of the data reviewed and analyzed by the Director of Health Services for medication occurrences, health care records and deaths, and summary reports of the State’s Director of Human Rights reviews of all restraint reports.

6. According to the information provided for the quality review, 86 percent of individuals living in community homes reported they received the services they need. Provide additional information regarding this outcome data including steps taken to improve outcomes for access to services. What specific action is taken to ensure that individuals in residential facilities where aversive treatments are used are able to participate in their service planning?

7. The quality review material submitted for the CMS review included the following assertions: 1.) The waiver program “obviates” the need for institutional care. 2.) “The [quality] system is designed to create a continuous presence with individuals and providers.” 3.) The State provides for “Rigorous measurement of health, safety, and human rights,” and “Significant emphasis on other qualities of life domains including community integration, relationships, choice and control and accomplishments.” Please explain how these elements of the State’s quality monitoring and oversight are assured with regard to Medicaid and HCBS waiver eligible individuals receiving residential habilitation and other services provided by HCBS waiver service providers authorized to use aversive procedures.

8. The quality information provided by the State indicated that the Medicaid Director is responsible for coordinating the overall administration and support of the MassHealth program across all EOHHS agencies, including the Department of Developmental Services. Please describe coordination of efforts among these agencies, and coordination between these agencies and the State Department of Education and other agencies serving children and people with disabilities, specifically with regard to ensuring the health and safety of people residing in residential facilities under the regulatory authority of the State. Include information about coordination of responses to information provided by mandated reporters to the Disabled Persons Protection Commission.

9. The information provided for the quality report indicated that 94 to 95 percent of individuals receiving HCBS waiver services knew how to report abuse and neglect, and that service providers were required to provide training to people who did not know how to do this. Please provide details regarding your follow up activities to ensure the required remediation occurred.

10. The media reports concerning the Judge Rotenberg Center allege that staff are able to “drop” services from the care plans of individuals at the center, including therapy services. Please describe fully how the State ensures that individuals are provided all medically necessary services and all needed HCBS waiver services. Include an explanation of the role of case managers and Supervisory case managers in ensuring that the Federal waiver assurances for Service Planning are met.