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March 6, 2007

The Honorable Judge Joseph L. Tauro
United States District Court
John Joseph Moakley U.S. Courthouse
1 Courthouse Way - Suite 2300
Boston, MA 02210

Re: The Monitor's Report on Whether the "Past and Prospective transfer processes employed by the Department of Mental Retardation were in compliance with Federal Law, State Regulations, as well as Orders of the Court."

Dear Judge Tauro:

I am writing you in my capacity as Court appointed Monitor in the Fernald matter. Since the appointment in February, 2006, our office has conducted extensive visits to all of the Commonwealth's Intermediate Care Facilities for the Mentally Retarded (ICF/MR) within Massachusetts, including four visits to Fernald, and visits to Hogan, Monson, Templeton, Wrentham and Glavin. We have met with well over 250 guardians, parents and siblings at Fernald and other ICF/MRs, and have visited with and met with most of the residents of these facilities during their day programs and in their residences. In addition, we visited over 30 community residences and numerous day centers. We have also reviewed all of the pleadings in the Ricci v. Okin, et. al. filings, and ascertained that there are approximately 3,959 Ricci class members. Overall, 49 individuals were transferred from Fernald since February 26, 2003 with 35 transferring to ICF/MRs and 14 transferring to community residences.

While our review touched on a number of issues raised by plaintiffs and guardians, two areas of significant concern were delivery of medical services and the potential for greater abuse

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and neglect in the community.

To best understand how medical services are provided for individuals residing in community residences, and how investigations of alleged neglect and abuse are conducted, our office received two presentations from the Department of Mental Retardation (DMR) on Medical Services to Ricci Class Members in the community, and how Allegations of Abuse and Neglect are Investigated by DMR. Our office invited all of the plaintiffs' counsel to attend the presentations, and thereafter, solicited written comments and questions from plaintiffs' counsel. Upon receipt of the plaintiffs' comments and questions, our office asked DMR to respond in writing. These presentations, and the follow-up questions and answers, gave our office tremendous insight into how medical services are accessed by mentally retarded individuals in community residences. The presentation on how Allegations of Abuse and Neglect are Investigated was extremely informative. We also independently reviewed the Disabled Persons Protection Commissions Vendor Survey Reports for all ICF/MRs and for community residences since January, 1996. We met on a number of occasions with counsel for the parties and conducted bi-weekly conference calls. We requested and were provided assistance from counsel and the parties to better appreciate the issues, challenges and successes as it related to the services provided to our most vulnerable citizens. Overall, the review by the Monitor attempted to meet the scope of review defined by the Court. Our approach was to achieve a full understanding of the various arguments and allegations being raised by the plaintiffs, in order to provide the Court with a more comprehensive report.

1. **Overview of the Intermediate Care Facilities for the Mentally Retarded (ICF/MRs)**

A. **The Hogan Regional Center**

Our office visited the Hogan Regional Center at 450 Maple Street, Hathorne, Massachusetts. Our office was extremely impressed with the facility and the level of comprehensive medical care that is provided to each individual. The facility has an extremely functional design and is situated on 54 acres. The facility was opened in 1967 and is presently home to approximately 151 individuals and has a capacity for 166 individuals. The physical layout consists of several discrete residential units and vocational work sites with a central gymnasium, pool, cafeteria, auditorium and motor training area. The facility is Title XIX

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qualified and is capable of providing service coordination dependent upon an individuals assessed needs. These needs could include the following: Assistive Technology, Audiology, Dental, Medicine, Neurology, Nursing, Nutrition, Occupational Therapy, Orthotics, Orthopedics, Peripatology, Physical Therapy, Psychology, Social Services, Speech Therapy, Therapeutic Recreation and Vocational Services.

The Day Program at the Hogan Regional Center is directed by North Shore Enterprises. The program is conducted in two buildings and over half of the individuals at Hogan attend the program. The remaining individuals at Hogan attend day programs in the community between 9:00 a.m. and 3:00 p.m. The day programs range from very basic skill building to pre-vocational skills.

The Hogan Regional Center is well maintained and exhibited bright cheerful artwork throughout the facility. We noted that the staff takes great pleasure in making each living area as comfortable and well decorated as possible. This feeling of home was a recurrent theme throughout all of the ICF/MRs that we visited.

B. The Wrentham Development Center

Our office visited the Wrentham Development Center at 131 Emerald Street, Wrentham, Massachusetts. We were extremely impressed with the facility and the level of comprehensive medical care that is provided to each individual. The facility services approximately 325 adults with mental retardation and has a capacity for 343 individuals. It opened in 1907 and is situated on 400 acres of open and wooded land. The configuration of the facility includes 5 large buildings and 13 houses. The facility also has a state-of-the-art 12 bed acute care medical center. The medical center is also used for diagnostic evaluations, reassessment of chronic illness, and/or close medical or nursing observation. Overall, the facility offers a full range of clinical services in the area of medicine, nursing, psychology, recreation, social work, occupational and physical therapy, communication, adult education and vocational services.

The Wrentham Development Center also houses the Quinn Program Center for workshops and day activities. Such activities include vocational, recreational and other learning and interactive programs. The complex has an Olympic size indoor pool with one-third of the pool having a floor that is adjustable from depths of zero to four feet of water. The building also has a full size

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gymnasium with all the modern exercise equipment and is overseen by adaptive physical education instructors.

The Wrentham residences are very nicely decorated and it is obvious that the staff takes great pride in making each residence very warm and inviting.

C. The Monson Development Center

Our office visited the Monson Development Center at 175 State Avenue, Palmer, Massachusetts. The facility was originally opened in 1898 as a hospital for people with epilepsy. Until 1970, epilepsy was the common and primary diagnosis for everyone admitted to the facility. Epilepsy and its treatment often result in the development of many other health conditions, and consequently, Monson has developed sophisticated medical services and supports to address the complex medical needs of its residents. The facility is situated on 588 acres and is located one mile from the Massachusetts Turnpike. Monson is a Title XIX consent degree facility that currently supports 186 people with a capacity for 385 people.

The age range for residents at Monson is between 35 to 87. The functioning ranges for the residents are between profoundly mentally retarded to mild, with 79% of the population functioning in the severe to profound range. The facility has around the clock nursing including 4 nurse practitioners and 2 physicians on duty between Monday through Friday. There is an on call physician coverage for nights and weekends. Other clinical services provided include Occupational Therapy, Physical Therapy, Adapted Equipment, Psychology, Speech Therapy, Habilitation Coordination, Recreation, Nursing, Respiratory Therapy, Neurology, Podiatry, Optometry, Psychiatry and Gynecology. Monson uses The University of Massachusetts Medical Center and The Wing Memorial Hospital for acute care hospitalizations. Monson also has an on-campus hospital, which often shortens stays in acute hospitals, and provides extensive health services for people experiencing acute problems. Monson has an array of day programs including competitive employment, employment workshops, retirement services and sensory motor programs.

Although Monson was opened in 1898, the facility has undergone continuous renovation since 1975. Some of the improvements included upgrading electrical and water systems, renovating 15 living areas and permitting decorations and furnishings to reflect the personal preferences of the residents and their

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families. There is a strong sense of pride within the facility and it is evident in the longevity of the work force as the average years of employment at the facility is 20 years, and the average age of the employees is 45 years (we noted similar employment trends at the other ICF/MRs).

D. The Glavin Regional Center

The Glavin Regional Center in Shrewsbury was opened in May, 1974 and is situated 123 acres on Lake Street, Shrewsbury, Massachusetts. Each of the approximate 63 resident receives residential and day programs. Glavin has a capacity of 63 residents. The programs are certified yearly by the Department of Public Health under Federal Title XIX Regulations. Although Glavin Regional Center did not come under the consent decree, approximately 18 residents who presently reside at the center are class members. The age for people living at Glavin ranges from 31 to 83. Glavin has the capacity to provide a variety of professional services including nursing, physical therapy, occupational therapy, psychology, psychiatry, speech and language pathology, vocational and recreation therapy.

Glavin is located high atop a hill with magnificent surrounding views. The facility is bright, cheerful, well decorated and located just off of Route 9 in Shrewsbury.

E. Templeton Development Center

The Templeton Development Center is located 70 miles west of Boston on 2,600 acres in Baldwinville, Massachusetts. Templeton is a Title XIX certified, state operated intermediate care facility that supports 143 adults with mental retardation with a capacity to support 160 individuals. Templeton, a Consent Decree facility, was originally developed as an extension of the Walter E. Fernald State School in May 1900. In 1992 Templeton became an independent facility known as Templeton Development Center. Templeton provides services for individuals ranging in age from 26 to 91. Templeton's residences are comprised of six lodges and three small 8-person homes. Templeton is an agricultural community that has the capacity to provide medical and clinical services to individuals with physical and emotional issues associated with the aging process. Templeton's medical services are provided by Shriver Clinical Group, Henry Heywood Memorial Hospital and The University of Massachusetts Medical Center. Templeton utilizes twenty-four hour nursing coverage, two physician's assistants and a community based medical practice

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for on-site medical care. Dental service is provide on-site through a contract with Tufts Dental.

Templeton has developed highly specialized supports to assist and treat individuals with challenging behavioral issues. All individual supports are provided through the ISP team process. An ISP team composed of a QMRP, Nurse, Physician's Assistant, Social Worker, Psychologist, Recreational Therapist, Adult Educator, Vocational Rehabilitation Counselor, Occupational Therapist, Physical Therapist and Speech Pathologist. The facility provides on-site educational and vocational supports through four day programs and six vocational programs. Two of the on-site vocational programs provide training in the areas of dairy operation and farming. The facility also operates a productive dairy/beef program and a gardening program.

F. The Fernald Center

The Fernald Developmental Center is distinguished as the Western Hemisphere's oldest publicly-funded facility serving individuals who have developmental disabilities. Fernald is located on 186 acres in Waltham. Fernald's services concentrate on encouraging each resident to learn and grow by participating in a variety of programs designed to develop social, work and daily living skills. Between 1924 and 1970, Fernald became a site for expanded research into the causes of mental retardation, resulting in the opening of Shriver Center on the Fernald grounds in 1970. In 1974, Fernald entered into the Medicaid (Title XIX) program and into a consent decree process. Since that time, dramatic improvements have taken place in the quality of the residents' lives, and in the quality of services they receive. In 1993, Fernald merged with the Metro Boston Region with a focus on opportunities in the community for individuals. In 1998 the Walter E. Fernald State School campus became known as The Fernald Center to reflect both the Fernald Developmental Center and the Marquardt Skilled Nursing Facility.

The individuals who live at Fernald have a range of developmental disabilities and most function at the profound level of retardation. As of September, 2006, there are 189 residents at Fernald and 29 resident at Marquardt with the age range of 35 - 94. The individuals who live at Fernald live in homes with groupings of 5 to 16. Thirteen buildings, including the Marquardt Nursing Home are currently used for residential housing. Six sites are used for vocational training and recreational pursuits. Fernald's residents receive services on

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and off grounds, ranging from leisure-based retirement programs to supportive employment. All Fernald residents receive some form of social security assistance and are covered by Medicaid. The Fernald Center employs more than 774 staff in administrative, direct care, clinical and support services positions. About 85 percent of the staff are engaged in direct care services. Fernald provides supports and services 24 hours a day. A team of direct service staff and clinicians work together to meet the individual needs of the individuals who live at Fernald. The teams may include speech, occupational, physical and recreation therapists, direct care staff, adult education, psychology, nursing, medical and nutrition staff. By being in compliance with Title XIX Acts of 1974, Fernald receives Federal reimbursements. Some of the resources at the Fernald Center include an indoor handicapped accessible pool, gymnasiums, Activity Center and a ballfield.

2. Residential Placement Options Within Community

- A. Residential placement options within the community are divided into essentially three options including supervised living, shared living and family partnership.
- (i) Supervised Living - If a family chooses supervised living they have a preference between a provider operated program or a state operated program. Typically, individuals can live in a home with anywhere from 1 to 5 other individuals. Each home has a house manager and direct support staff. Dependent upon the needs of the people living in the homes, there may be a nurse working in the home or available to the home. Staffing varies depending on the support needs of the individuals, but typically there are 2 direct support staff for 4 individuals. These homes have their own vehicles for transportation.
 - (ii) Shared Living - Individuals have the option of living with a care provider in the care provider's home. The care provider can be single or have a family, and the provider is paid to support the individual. Oversight of such a living situation is provided by a residential support provider agency that provides placement, guidance and oversight.

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(iii) Family Partnership - A family partnership is an individual or family-directed cooperative arrangement in which a DMR consumer or his or her family provides or contributes toward the cost of a residence in which the Department provides or arranges for services to be provided. The arrangement provides individuals and families with greater choice and control over where a family member lives and will receive services such as in their childhood home or a particular area where an individual grew up or has community connections.

B. Community Day Supports

- (i) Community-Based Day Supports - These supports are provided to individuals who qualify for DMR services during the workday hours in lieu of employment supports. These services offer individuals an opportunity to develop, enhance and maintain their competence and confidence in personal, social and community activities. Individuals who are medically fragile or have other significant health, mental health or behavioral issues that limit their ability to be engaged in productive work activities.
- (ii) DMA Day Habilitation - A structured, goal-oriented active treatment program of medically oriented, therapeutic, and habilitation services that are intended to raise individuals' level of functioning and facilitate independent living and self-management in their home communities.
- (iii) Employment Supports - Employment supports are for individuals of all abilities. Supports assist individuals to prepare for and experience gainful employment, and may include sheltered employment, work crews, enclaves, provider-owned businesses, volunteer work, provider-paid employment, and supported employment, with the overarching goal of quality jobs for individuals.
- (iv) Competitive Employment - This is full or part time paid work, which is done either in the public or private sector. Such work is not supported in any

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way by DMR. Individuals who work competitively are on company payroll and may be eligible for all employee benefits.

- (v) DMA Adult Day Health - A program to provide an alternative to 24-hour long term institutional settings through an organized program of health care, supervision, restorative services, and socialization. The Division of Medial Assistance administers this program.
- (vi) DMH Day Program - This Psychiatric Day Treatment Program is a planned combination of diagnostic, treatment, and rehabilitative services provided to mentally or emotionally disturbed individuals who need more active or inclusive treatment that is typically available through a weekly visit to a mental health center or hospital outpatient department, but who do not need full-time hospitalization or institutionalization. Such a program utilizes multiple, intensive, and focused activities in a supportive environment to enable individuals to acquire more realistic and appropriate behavior patterns, attitudes, and skills for eventual independent functioning in the community. Such programs may be operated by a freestanding clinic, a satellite facility of a clinic, a hospital licensed health center, or an identifiable unit of a clinic, hospital, or hospital licensed health center.
- (vii) MCB Day Programs - This Day/Work program is funded and operated by the Massachusetts Commission for the Blind (MCB).
- (viii) MRC Employment and Training - These are Massachusetts Rehabilitation Commission (MRC) funded employment supports that include extended employment (EEP) at a private rehabilitation facility. This program offers supported employment in an integrated work setting, or transitional employment work experiences at a business or industry for the purpose of providing evaluation, training, and supervision.

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3. Review of Medical and Clinical Services at the ICF/MRs and within the Community

In an attempt to independently glean a full understanding of the medical and clinical requirements of individuals seeking to transfer from Fernald to other ICF/MRs or to community residences, our office hired independent medical doctors with a history of caring for individuals afflicted with mental retardation. We asked counsel for the plaintiffs and the defendants to provide a list of qualified medical professionals that had experience in treating and servicing individuals with mental retardation. Once the list was finalized, it was distributed to counsel for the plaintiffs and the defendants. A period of time was allowed for our office to receive comments, suggestions and concerns regarding the list of medical professionals. Three medical doctors with extensive experience servicing individuals with mental retardation were chosen by our office. Our office had extensive discussions with these doctors, and specifically discussed the ISP process and DMR's use of the ISP process for both present and future needs of individuals who have transferred from Fernald, and for potential prospective transfers.

A. Medical Professionals Hired to Assist the Monitor

Lawrence W. Osborn, M.D., MPH, is the Associate Medical Director for Geriatric Psychiatry at Providence Hospital and Mercy Medical Center. He was a Commissioned Medical Officer for the United States Public Health Service between 1968 - 1988. He was the National Medical Director for Mental Health, U.S. Healthcare (then Aetna-U.S. Healthcare) between 1992-2001.

Dr. Robert Baldor is a Board-certified family Physician and has a practice at the University of Massachusetts Medical School in Worcester. His current practice includes caring for individuals with intellectual disabilities, and he makes house calls to group homes where 4-8 individuals with mental retardation reside. He also worked at Belchertown Development Center when it was operational.

Paul Millard Hardy, M.D. is a physician licensed to practice medicine in the Commonwealth of Massachusetts since 1977. Dr. Hardy is board certified in Neurology by the American Board of Psychiatry and Neurology and received sub-specialty training in

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Neuropsychiatry at Boston University School of Medicine. In 1976 he was the Joseph P. Kennedy Jr. Fellow in Medical Ethics at Harvard University. The following year he joined the Eunice Kennedy Shriver Center and worked as physician and neurological consultant at the Paul A. Dever State School in Taunton, Massachusetts. During that time he assisted in the evaluation of residents for transition into the community under the jurisdiction of this Court. He was medical director at the Fernald State School from 1982 to 1985 and held academic appointments in the departments of neurology at Harvard Medical School and the Tufts University School of Medicine. At Tufts he also held an appointment in the Department of Psychiatry. In 1980 he began an outpatient clinic at Tufts New England Medical Center in neurology for community-based developmentally disabled persons and in 1992 formed his own practice in neuropsychiatry in Hingham, Massachusetts where he has cared for many developmentally disabled individuals in the community.

B. Document Review Conducted by the Medical Professionals

The medical doctors reviewed various documents and reports for each of the transferred individuals to assist our office in our investigation. Some of the documents reviewed included, but were not limited to, the following:

1. Results of Recertification Survey for Title XIX ICF/MR of Walter E. Fernald Developmental Center;
2. Results of Recertification Survey for Title XIX ICF/MR of Wretham Developmental Center;
3. Results of Recertification Survey for Title XIX ICF/MR of the Hogan Regional Center;
4. Results of Recertification Survey for Title XIX ICF/MR of the Monson Development Center;
5. Results of Recertification Survey for Title XIX ICF/MR of the Glavin Regional Center;
6. Results of Recertification Survey for Title XIX ICF/MR of the Templeton Development Center;
7. Medication and Routine Physician Orders;
8. Fernald Center - Title XIX Annual Medical Review per

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- individual;
9. Annual Physical Examinations;
 10. Psychiatric Clinic Notes;
 11. Mental Health Care Team Reports;
 12. Orthopedic Clinic Notes, Cardiology Services Reports, Radiologic examination reports and audiologic evaluation reports;
 13. Tufts Dental Facility Reports;
 14. Health Transfer Plans for each individual -- Covering Primary Care, Audiology, Dental, Orthopedics, Ophthalmology and Psychiatry. These reports identify client-specific resources at the new location available to meet an individual's assessed needs, both current and future;
 15. Individual Transition Plan for each individual (the ITP covers Personal Characteristics, Special Information for Personal Routines, Social Life, Relationships and Communication, Physical Considerations and Equipment Needs, Safety Considerations, Health/Medical/Psychological Needs, ISP Reviews Transition and Fire Safety Forms, and OT/PT Team Reviews);
 16. Individual Support Plan Meeting Reports;
 17. Letters and Information Packets on each individual from The Fernald Center to Family Members/Guardians and/or Representatives;
 18. Internal letters and information packets regarding individuals moving from one ICF/MR to another ICF/MR, and from an ICF/MR into a community residence; and
 19. Characterization of Retardation Level and Psychological Assessment for each individual.

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4. The Monitor's Findings

Our office was asked by the Court to conduct an investigation into whether the "past and prospective transfer processes employed by the Department of Mental Retardation were in compliance with Federal law, State regulations, as well as Orders of the Court."

A. DMR's Certification of Equal or Better Services

The plaintiffs have alleged that DMR is in violation of the Final Order of the Court entered on May 25, 1993, because the Facility Director of Fernald is not certifying that individuals to be transferred will receive equal or better services at their new residences. The plaintiffs are also alleging that the Facility Director is not certifying that ISP recommended services for the individual's current needs are available at the new location (see: Pleading #83, p. 4 of 21).

DMR has responded by stating that "the completed Individual Service Plan, in conjunction with the ISP Process represents the certification by the Facility Director (Linda Montminy) that the Individual's needs are being met in the new location" (Letter from Marianne Meacham to Beryl Cohen dated September 26, 2005; and Pleading #86, p. 13, Section C; Diane Enochs Aff. ¶ 10).

The 1993 Final Order of the Court provides as follows:

"Defendants shall not approve a transfer of any class member out of state school into the community, or from one community residence to another such residence, until and unless the Superintendent of the transferring school (or the Regional Director of the pertinent community region) certifies that the individual to be transferred will receive equal or better services to meet their needs in the new location, and that all ISP-recommended services for the individuals current needs as identified in the ISP are available at the new location."

Ricci v. Okin, M.D. et. al., 823 F.Supp. 984, 987 (D. Mass. 1993).

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Our office noted that the Court did not specify how the certification must be made, but it is clear that certification must be made. The Final Order is also silent on whether certification is required when transferring from one ICF/MR to another ICF/MR. Given these parameters, our office conducted an investigation into how the Facility Director certified that services currently being received would be duplicated and perhaps better at the new residence.

Our office independently verified that DMR, through its Facility Director, has certified for the 49 individuals transferred previously, that services will be equal or better. This certification was made through the Facility Director's review of objectives of an individual's current ISP as compared to their new ISP at the new location. Following January, 2005 DMR implemented a return to an explicit certification of equal or better services in the Ricci Change of Address Form for any transfers of class members. Our office also had the medical doctors that we retained review the ISPs of the individuals that transferred from Fernald to determine if the services received after the transfer met their needs.

Of note is DMR's position that transfers from an ICF/MR to another ICF/MR do not require a certification of equal or better because such certification is not required by the Final Order. Although the Final Order is silent on this specific scenario, our office found that all of the ICF/MRs were Title XIX certified. Each facility currently has the minimum services, staffing and amenities to provide equal or better services. As expected, each ICF/MR has its own individual character and differing degrees of specialized services. The staff at all the ICF/MRs are extremely experienced and long tenured.

Through our tours of various community homes we witnessed services consistent with the Court's Final Order including the following: "residential programs; day programs; recreational and leisure time activities; medical, psychological, dental and health-related professional services; respite care and crisis intervention services; support and generic services, such as guardianship and adaptive equipment services; and transportation services." Ricci, 823 F.Supp. at 987. The medical doctors that we retained also confirmed that these services are available in the community, and reviewed the housing, health, employment and occupational needs of the clients. Individuals transferred to the community can receive these services equal or better than at the ICF/MRs.

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While the services that are listed in the Final Order are available in the community, the issue is evaluating how these services are accessed and delivered, what the wait time is for these services and where the services are located as compared with where the individual resides and how that may impact on an individual basis "equal or better." Our office received a presentation from DMR regarding Medical Services to Ricci Class Members in the Community. This presentation shed light on how an individual in a community residence actually sees a physician and receives dental care. In the community residences the direct care staff makes the arrangements and appointments for a specific resident. Ultimately, this process takes much longer than the process at Fernald and is more difficult to coordinate (i.e. our office noted that community residences have one wheelchair adaptive vehicle assigned per house. If this vehicle has to be used for pick-up and drop-off of other residents from day programs, coordination must be made with other vehicles operated by the provider). Based on the information provided one could not conclude that quicker access to medical care in and of itself equated to better care (the bedside manner of the community doctor located 20 minutes away could be better than the facility doctor that is on call, or just the opposite could be the case). But, given the physical limitations, and fragile emotional state of members of this population, coupled with a reduced mental capacity to communicate and explain an increase or decrease in the intensity of an ailment, we certainly understand the potential risks and why some guardians would prefer to have their ward in an ICF/MR and have a facility doctor on call.

An individual living in a community residence attends day programs outside of the residence. Some day programs offer a myriad of services during the day program including speech therapy, physical therapy and occupational therapy. Our office did note that some therapy, such as aquatic therapy in a heated room with a heated pool, are more difficult to access in the community. Aquatic therapy can be duplicated in the community but with effort.

Lastly, DMR organized tours of community residences throughout Massachusetts for our office. Counsel for the plaintiffs were invited to attend these tours. Our office also toured specific community homes at the request of counsel for the plaintiffs. Our tours revealed well maintained homes in very nice neighborhoods. The staffing patterns varied dependent upon the needs of the residents. Our office did note that the tenure of most House Managers within community residences was less than 3

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years, with 5 years being a rarity. Staff turnover was in some instances 100% every year and a half. Repeatedly, our office heard, from guardians and providers, that an on-going struggle is to maintain the continuity of staffing for better on-going care. The direct cause for the high turnover rate was the challenging work coupled with the low pay scale.

Guardians were present on some of the tours to discuss their experience of having their ward/family member in a community home. Some of the comments we heard included the joy of having their ward in his/her own home; having his/her own room to decorate with personal belongings without having something disappear; being closer to family and friends and taking advantage of community events; being able to cook in the kitchen, interact with the same roommates and being part of a community around the home. The recreational activities varied from home to home but essentially involved community activities such as summer concerts, picnics, shopping at the mall, going to restaurants, arts and crafts, holiday and birthday parties at the home and walking through the neighborhood. While one goal of the community residences is to integrate adults with disabilities within the community, a bedroom in a neighborhood home does not guarantee integration into the fabric of a neighborhood or a community. It takes an effort and commitment on the part of the provider to maximize these opportunities. From the perspective of DMR, as well as the guardians and the residents, community placement for many individuals has been a great success.

Given that medical and rehabilitative services, outlined by the Court's Final Order, can be met within the community, albeit through the more labor intensive methods used by direct care staff, our office found that DMR was in compliance for the transferred residents with certifying equal or better services in the community. It is important to note the vulnerability of many of these residents. Though those already in community homes appear to have adapted well, many seem younger than the average age of those still residing at ICF/MRs.

Unfortunately, after reviewing data from the Disabled Persons Protection Commission, our office did note some very concerning neglect and abuse trends in Contract Vendor operated community residences, as compared to the ICF/MRs and State operated community residences. These neglect and abuse trends, particularly sexual abuse, were of great concern to our office

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and shows that residents in our community homes are at a greater risk of being abused and/or neglected.¹

B. The Green United States Postal Service Registered Mail Cards (Sent with the "Notice of Request for Proposed Facility Transfer" letter Returned to DMR with the Guardian's Signature).

Our office independently reviewed each file of the individuals transferred and found that DMR was in compliance with documenting the properly signed returned receipt of each Registered Mail Card from guardians.

C. Notice of and Request for Proposed Facility Transfer ("45-Day Letter")

(i) Documentation that 45-Day Letter was sent to Guardians

Our office independently reviewed each file of the individuals transferred and found evidence that the 45-Day Letter was sent to "individual's family, guardian, and designated representative" pursuant to 115 CMR 6.63.

(ii) Receipt of the 45-Day Letter

Our office independently reviewed each file of the individuals transferred and found that DMR was in compliance with documenting the receipt of Notice of and Request for Proposed Facility Transfer Letter pursuant to 115 CMR 6.63(2) of the Department of Mental Retardation Transfer Regulations. The letters are

¹ The Disabled Persons Protection Commission provided our office with Vender Survey Reports for all ICF/MRs dating back to January, 1996. We also reviewed Vender Survey Reports for State operated community residences and Contract Vendor operated community residences dating back to 2002. Our office noted that over the years there was a steady increase in allegations of sexual abuse and physical abuse in Vendor operated community residences. The highest levels of sexual abuse occurred with the transportation providers for the Vendor operated community residences. Physical abuse was much higher in Vender operated community residences than in the ICF/MRs. Our office also noted that unreported incidents of abuse may even be higher in community residences due to the non-verbal nature of the clients. Lastly, there was very little to no sexual abuse noted for all of the ICF/MRs.

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complete with all the information required by the Regulation, and clearly provided guidelines for the appellate process (115 CMR 6.63(4)) before the Division of Administrative Law Appeals if the ward's ISP could not be fully implemented as a result of her guardian's objection to the proposed transfer.

Our office also noted that pursuant to 115 CMR 6.63(2)(c) and 115 CMR 663(2)(d) 2 and 3, that each guardian, through their consent to the proposed facility transfer, waived the 45-day waiting period.

Our office did not find any evidence that the 45-Day Letter was delivered to other parties, as described in 115 CMR 6.63(2)(a). Our office could not determine who, other than the legal guardian, would be entitled to receive this Letter. A copy of this Letter is maintained in the individual's permanent file at Fernald.

(iii) The Right to Visit and Examine the Proposed Homes

Our office found that although the specific language providing a right to visit was not always present in the 45-Day Letter for proposed moves, most of the guardians indicated that they had visited the new proposed residences. Our office would suggest that DMR insert the right to visit language in every 45-Day Letter whether or not a guardian has visited the proposed ICF/MR or proposed community residence. The specific language in 115 CMR 6.63(2)(c)(3) is as follows: "include a statement that the parties may visit and examine the proposed home at a time and in a manner not disruptive to individuals who may be living in the home."

(iv) Language within the 45-Day Letter Inviting Guardians to Consult with Service Coordinators and Other Staff Regarding the Advantages and Disadvantages of the Transfer

Our office independently reviewed the files of all the individuals that transferred and found language in each 45-Day Letter identifying the telephone number for the DMR Service Coordinator/QMRP, and other individuals working for DMR available to discuss with the Guardian the new ICF/MR or community residence. DMR is in compliance with 115 CMR 6.63(2)(c)(4).

(v) Allegations of DMR Violating 42 CFR 483.12 (Code of

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Federal Regulations)

Our office did not find any violations by DMR of 42 CFR 483.12. Specifically, these regulations pertain to the admission, discharge and transfer standards for skilled nursing facilities and nursing facilities in general, and do not address the transfer of residents from ICF/MRs.

(vi) DMR's Consultation with the Guardians of the 49 Transferees

Our office has verified that DMR received the consent of all of the guardians for the transfer of all 49 individuals from Fernald. Some of these Guardians, representatives and family members were located out of state, and thus there was a varying level of involvement of each individual.

(vii) The Right to Return Letter

Our office found that for individuals being transferred from Fernald to another ICF/MR, DMR did not provide the Guardians with a Right to Return Letter. DMR's position was that these individuals were not transferring from an ICF/MR to the community and thus it was not necessary to provide the Guardian with a Right to Return Letter.

Our office identified six individuals transferred from Fernald following the Court's June 15, 2005 hearing making it clear that anyone who leaves can return if they choose. Following this hearing, approximately six individuals were transferred from Fernald to the community and each individual's file contained a Right to Return Letter. Prior to this hearing date, such a letter was not routinely provided to Guardians of individuals that transferred from Fernald to the community.

(ix) Informed Consent Regulations

The plaintiffs allege that DMR failed to comply with State regulatory requirements to obtain knowing consent, voluntarily given by an individual's guardian, of the advantages and disadvantages of the proposed move. Specifically, the plaintiffs contend that DMR has failed to comply with 115 CMR5.08(1)-(3) by utilizing a blanket consent form that states as follows:

"I (guardian) have received timely notice of the

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proposed transfer pertaining to (individual) from (place) to (place) on or about (date) pursuant to 115 CMR 6.63(2) of the regulations of the Department of Mental Retardation. I have also received notice of my rights under these regulations. I understand my right to deny consent to the proposed transfer and my right to a hearing. After considering the information I have received about the proposed transfer, I am satisfied that this transfer is in (individual's) best interest. All my questions have been answered to my full satisfaction. I, therefore, choose not to object and hereby consent to the proposed transfer."

(Pleading #83, p. 9).

DMR responded by stating that plaintiffs are relying on regulatory provisions for "informed consent" that pertain to admission to a [nursing] facility or prior to medical or other treatment that requires the risks and benefits of admission or medical treatment. DMR's position was as follows:

"The Fernald Plaintiffs erroneously contend that the voluntary transfer of an individual from a Department facility requires the "informed consent" of the individual or guardian. "Informed consent" is a term of art defined in the Department's regulations, and is required only in limited instances and is generally reserved for medical procedures, research activities, facility admissions or related activities. See 115 CMR § 5.08. Transfer from one setting to another requires consent, not "informed consent" as defined in 115 CMR § 5.08; nevertheless, the 45-day letter and consent form the Department provides during the transfer process clearly meets this standard as well as the standard set forth in 115 CMR § 2.01's definition of "consent." "

(Pleading #86, p. 25 fn. 13).

Our office found that pursuant to 115 CMR 5.08, informed consent of an individual, or a guardian, is required (a) prior to admission to a facility; (b) prior to medical treatment; (c) prior to involvement of an individual in research activities; (d) prior to level II or III behavior modification interventions; and (e) prior to the release of personal information. In addition, the person securing consent shall: (1) explain the intended outcome and nature of procedure involved in the proposed

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treatment; (2) explain the risks, side effects of treatment or activity; (3) explain the alternatives to the proposed treatment; (4) explain that consent may be withheld or withdrawn; (5) present the information in a foregoing manner understood by the individual; and (6) offer to answer additional questions.

Informed consent is a term associated with medical procedures, not requests to transfer. The doctrine of informed consent imposes on a physician the duty to explain the procedure to the patient and to warn him of any inherent risks or dangers, it is specific to the medical procedure and is not intended to be used synonymous to the requirement of consent. See Kissinger v. Lofgren, 836 F.2d 678, 680 (1st Cir. 1988) (explaining doctrine of informed consent in Massachusetts requires a plaintiff to establish (1) the existence of a duty owed by the defendant to inform about significant risks, consequences, and options of a medical treatment, and (2) that breach of this duty caused harm to plaintiff). Requiring "Informed Consent" is specific to medical procedures and treatments. See Rosaria v. U.S., 824 F. Supp. 268, 286 (Mass. 1993) (explaining the doctrine of informed consent derives from the notion that a person has a strong interest in being free from non-consensual invasion of his bodily integrity; person needs to make an intelligent decision whether to proceed with a specific course of treatment); Goldstein v. Kelleher, 728 F.2d 32, 39 (1st Cir. 1984) (finding that informed consent rest on foresight, not hindsight, where patient would not have undergone medical procedure had she known the risks); Harrison v. U.S., 284 F.3d 293, (1st Cir. 2002) (finding that a physician must disclose any material information to enable patient to make an informed judgment whether to give or withhold consent to a medical or surgical procedure).

DMR's Notice of and Request for Consent to proposed Facility Transfer letter in fact complies with the consent requirement for transfers involving non-medical circumstances. 115 CMR § 5.08 requires informed consent for medical procedures and other potential invasion tactics or procedures such as Level II or III modification interventions (restraining an individual) or involving a person in research activities. This is not similar to a guardian providing consent to have his/her ward transferred to another ICF/MR or a community residence.

Lastly, the plaintiffs rely on 42 CFR 483.12 as stating that DMR failed to comply with this Regulation prior to transferring 49 individuals. 42 CFR 483.12 governs specialized services for mental illness or mental retardation for persons found to require

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care within a skilled nursing facility. We did not find that this Regulation applied to ICF/MRs. see also Rolland v. Romney, 318 F.3d 42 (1st Cir. 2003)(holding the Commonwealth is responsible for providing specialized services that result in active treatment when combined with services provided by nursing facilities); Rolland v. Cellucci, 138 F.Supp.2d 110 (D. Mass. 2001)(The State was required to provide specialized services to the mentally retarded regardless of whether they resided in private nursing homes or state-owned facilities).

Our office did not find that DMR initiated any transfers without the full knowledge and consent of guardians. There were no allegations from any of the guardians, or from our medical doctors, that there were any unmet active treatment needs for the individuals transferred.

**D. Post Placement Satisfaction Surveys from
Guardians of the Transferees**

All of the individuals that responded to the Post Placement Satisfaction Surveys affirmatively stated they participated in planning for their ward's placement. The surveys were measured by numerical rankings with #1 being the most favorable and #5 being the least. The ratings were as follows:

- (I) 78% rating #1
- (ii) 14% rating #2
- (iii) 2% rating #3
- (iv) 1% rating #4
- (v) 1% rating #5
- (vi) 4% not rating at all but writing commentary.

The written commentary reflected extremely positive attitudes regarding the moves. A recurrent theme found was hesitancy to move from Fernald due to familiarity. Many of the guardians stated that they decided to transfer their ward from Fernald based on the announcement that Fernald will be closing. The comments were positive regarding the moves for a variety of reasons. There were recurrent themes of reduced care at Fernald due to staffing issues and low morale. The other ICF/MRs were praised for their wonderful staff, an improvement in services and environment. There was praise for the Fernald staff, particularly when it came to assisting in the transition, but the

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general sense was the lack of certainty in the closing of Fernald was causing problems.²

With regard to Guardians that preferred a transfer from Fernald to the community, the responses were also positive. Many Guardians reported an opportunity to visit their children, wards and siblings more frequently and at any time of the day. The responses to the surveys did not give the impression that there was any concerns or tendencies to seek a return to Fernald.

E. The Home and Community Based Services Waiver Program

The plaintiff's contend that DMR failed to fully explain the "Home and Community Based Services" Waiver Program to the guardians so that the guardians could make an informed consent to proposed community placement. Informed consent was discussed above in section ix, and our office found no Federal Law, State Regulations and any Orders of this Court requiring DMR to have a specific discussions with guardians on the Home and Community Based Services Waiver Program.

5. The Monitor's Final Assessment

DMR's directive to close Fernald has come with an offer by DMR for any resident seeking to remain at an ICF/MR, having the option of transferring to another ICF/MR. All of the ICF/MRs are Title XIX certified and DMR claims that they all have the capacity to potentially meet the need to provide equal or better treatment, care, professional services and medical treatment to all of the Fernald residents. With the appropriate involvement of family members and/or guardians, each resident at Fernald could be transferred to another ICF/MR to achieve the objective of closing Fernald, but clearly at a cost to individual residents. In this respect, DMR can duplicate the basic services and medical treatment for any resident at any of its ICF/MRs. Unfortunately, this solution does not solve the underlying problem.

The true issue plaguing the plaintiffs as a whole runs much deeper than simply transferring all of Fernald's residents to another ICF/MR. For many residents, Fernald is their home, the average age is 57 years, the average length of stay is 47 years,

² It should be noted that 6 individuals of the 49 individuals who transferred from Fernald died within 2 years of the transfers.

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the oldest resident is 95 and has been there for 81 years. The question is simply after all these years at this facility will their lives be equal or better if transferred elsewhere? As the guardians are getting older, they express both a fear and a mistrust. The guardians have expressed a fear of who will care for their loved ones, and a mistrust of whether promises made today will be broken in the future. The plaintiffs also claim that given the high level of sexual and physical abuse in the community, lack of accessibility to medical and dental services, along with high staff turnover and potentially less qualified staff, residential community homes are not the answer for many residents. Another concern is that although individuals in community residences supposedly have access to community activities, residing in the community does not guarantee that an individual will be integrated into the community. The plaintiffs fear that following Fernald's closing, Wrentham, Monson, Hogan, Glavin and Templeton will soon follow. The plaintiffs hold a genuine fear of years and years of shuffling sons, daughters and wards in an attempt to stay ahead of the next closure before being forced into community residences.

This very fragile segment of the Massachusetts' population strives for simplicity and constants to thrive and conduct their daily lives, and the threat of change does have an impact on the physical and emotional health of some of the residents. Similar to our old shoes that fit just right, or that favorite reclining chair that has molded perfectly to a body over the years, or the room and building we have spent our life calling home and those around us we consider family and friends, we all seek familiarity to ground our lives. We cherish these items for the indescribable comfort that they provide. For the severely mentally retarded, such a loss of familiar surroundings and most importantly people, could have devastating effects that unravel years of positive, non-abusive behavior. Moreover, the joy that each of us experiences from seeing the same person who serves morning coffee at the coffee shop, or that neighborhood person who greets you every morning for the past umpteen years, is also experienced ten fold by, in many cases, this segment of the population that has been cared for by the same State workers for ten, twenty and even thirty years in the ICF/MRs. Change for most of us comes at a cost, for the most vulnerable, the slightest change can have dramatic and permanent consequences.

Our office has been touched by the families willing to share their stories with us over the past year. The story of one mother and father who showed love and support for their

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son/daughter, and concerned that the closure of Fernald would mean a mad rush for the choice locations, decided to move their child. Their child had been cared for brilliantly at Fernald for over 40 years. Within one year, they received a call that their child was found on the floor and had died. Today, they ask themselves, in an attempt to do the right thing, had they failed their child by moving him/her after so many years of him/her flourishing at Fernald? The same fears grip others and for two Sundays and over twelve hours our office listened to such concerns by no less than 200 caring parents, sisters, brothers, aunts, uncles, guardians, nieces, nephews and friends. Our office has been inundated with pleas to keep Fernald open since now, through the Court's intervention, Fernald is a much different place and has reached respectable levels of care.

On one particular Sunday our office spent six hours listening to stories portraying Fernald during those dark years when the conditions were atrocious. Now, they proclaimed, Fernald is a place where people can thrive and truly call home. Faces are familiar and people have brought laughter to the halls and the programs. On another Sunday we were invited to morning Service by Father William Leonard. We were moved by the outpouring of young volunteers from the community that wheeled residents from the Green building across the street to the Chapel for Sunday Service. Those same volunteers either stayed or returned in time to escort the residents back to the Green building upon completion of Services. The community had embraced the residents at Fernald and the residents enjoyed their Sunday morning Service. Overall, we all work hard every day to provide comfort, stability and security for our families. We cannot imagine after residing in a home for thirty, forty or fifty years, and finally getting it to the point where you feel comfortable, stable and secure, that you are now told to pack up and move with potentially more moves to endure. Any of us would be outraged.

Today there are far fewer citizens in our ICF/MRS than a decade ago. For those that have moved into the community homes and are thriving this has been a good and important outcome. The Commonwealth in its attempt to address excess capacity is moving towards consolidation. There are other options that can address excess capacity and achieve some savings without resorting to closure of this facility.

In an attempt to find a solution for the Fernald residents, our office was surprised to find such vast acreage surrounding the various ICF/MRs. Glavin has 123 acres, Monson has 588 acres,

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Templeton has 2,600 acres, Wrentham has 400 acres and Fernald has 186 acres. At Fernald, it may be possible to group the homes and work sites of Fernald residents by dividing the buildings north of Pine Street and west of Cherry Lane and condense the campus. The Commonwealth could then sell the remainder of the land for residential development. DMR could also build some new residential homes on the land and have support services for these residents at Fernald.

Servicing individuals with mental retardation in ICF/MRs and the community each offers advantages and disadvantages to both systems. The model across the United States appears to be shifting toward housing the mentally retarded in community residences. Despite this trend, the strength that Massachusetts holds is allowing families to have a choice for their family members and wards. As this segment of the population ages, their parents and relatives are also aging. Many of the residents at Fernald have family members that live within close proximity to Fernald. We have met numerous individuals through our visits to Fernald that have expressed how difficult it would be for them to drive the distance to another ICF/MR to make that daily or weekly commute to visit their loved ones. Our office was amazed at the many residents at Fernald that have lived there for thirty, forty and fifty plus years. Many of the State workers can boast twenty or thirty years tenure at Fernald. These employees have become more than individuals waiting to achieve the benefits of State retirement, they are family to the residents who rely on them every day for the most basic needs that we take for granted. Breaking these decade long bonds is not the solution these residents deserve, nor should they be forced to experience countless moves given the conditions they had to endure before the Court's intervention.

Since the Monitor's Appointment in February, 2006, our office has witnessed outstanding medical and social care in all of the ICF/MRs. The quality of life for the ICF/MR residents is excellent, and this Court's persistence and insistence, over the past three decades, in raising the level of care for the mentally retarded is certainly remarkable. The Herculean effort shouldered by this Court since the early 1970s has, without doubt, enriched the lives of our mentally retarded citizens. This Court's effort is reminiscent of another monumental undertaking by the late Honorable Judge A. David Mazzone to revitalize Boston's Harbor as a waterway capable of nurturing and sustaining life. In many ways, this Court has accomplished the same task, as guardians of individuals residing within the

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ICF/MRs have provided our office with a clear understanding that the residents within these facilities receive the support that nurtures and enhances their quality of life.

As a result of a year long investigation, our office has concluded that some of the residents at Fernald could suffer an adverse impact, either emotionally and/or physically, if they were forced to transfer from Fernald to another ICF/MR or to a community residence. Our office would recommend the implementation of a development plan that would enable Fernald to remain open and provide services to some of the Commonwealth's most vulnerable citizens.

In summary, based on our review of all the conditions that are considered for "equal or better" services, it is the opinion of the Monitor that residents should continue to have the opportunity and option to move from Fernald to other ICF/MRs, or to a community residence, provided that the Certification Process is enforced. Additionally, and most importantly, considering the uniqueness of each of the ICF/MRs, and the vulnerability of the residents, Fernald residents should be allowed to remain at the Fernald facility, since for some, many or most, any other place would not meet an "equal or better" service outcome.

We are available at your convenience to provide any further information regarding this report. Thank you for the opportunity to assist the Court.

Sincerely,

/s/ Michael J. Sullivan

MICHAEL J. SULLIVAN
United States Attorney

/s/ Rayford A. Farquhar

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Deputy Chief
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