DEPARTMENT OF HEALTH & HUMAN SERVICES **OFFICE OF THE SECRETARY**

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Reference Number: [redacted]

Dear Director McMillian, Dr. Robinson and Ms. O'Connell:

The Office for Civil Rights ("OCR") of the U.S. Department of Health and Human Services ("HHS") has completed its investigation of a complaint filed by the Southern Disability Law Center ("Complainant") on behalf of [redacted] Grace ("Injured Party") against Mississippi Department of Rehabilitation Services ("MDRS") and the Mississippi Division of Medicaid ("MDM") (both referred to here as "the State"). The complainant alleged that the actions of MDRS and MDM constitute unlawful discrimination on the basis of disability in violation of Title II of the Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 *et seq.*, and implementing regulations at 28 C.F.R. Part 35 ("Title II"), and Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, and implementing regulations at 45 C.F.R. Part 84 ("Section 504").

Based on its investigation, OCR has concluded that MDRS and MDM have violated Title II of the ADA and Section 504 by failing to comply with the reasonable modification requirements established under those statutes. In addition, OCR has concluded that MDM and MDRS's refusal to modify [redacted] Plan of Care under the Traumatic Brain Injury/Spinal Cord Injury (TBI/SCI) waiver, without demonstrating that the requested modification would fundamentally alter the nature of its waiver program,

places [redacted] at risk of unnecessary institutionalization in violation of the Title II and Section 504 integration regulation.

The bases for OCR's findings are discussed in detail below.

I. Jurisdiction

OCR conducted its investigation pursuant to Section 504, and its implementing regulations codified at 45 C.F.R. Part 84, and Title II of the ADA, and its implementing regulations at 28 C.F.R. Part 35. As a recipient of Federal financial assistance, MDRS and MDM are obligated to comply with Section 504 and its implementing regulations. As a public entity, MDRS and MDM are also obligated to comply with Title II of the ADA and its implementing regulations.

II. Background

On September 18, 2009, Complainant filed a complaint with OCR on [redacted] behalf alleging that MDRS and MDM refused to provide him with the sufficient amount of personal care services under the TBI/SCI waiver, causing him to be at risk of institutionalization, in violation of the "integration mandate" of the ADA and Section 504. 28 C.F.R. § 35.130(d); 45 C.F.R. § 84.4(b)(2).[1]

Prior to his complaint to OCR, [redacted] experienced a long and complicated history with the Respondent agencies, including administrative appeals in which he challenged the State's repeated denials of his requests for additional attendant care services. This history will be explained below, along with pertinent details of the TBI/SCI waiver, prior to the discussion of the complaint filed with OCR and the State's response to this complaint.

[redacted] is 61 years old. In 1980, [redacted] was injured in a car accident in which he sustained a [redacted] spinal cord injury that left him paralyzed [redacted]. Because of this injury, [redacted] is totally dependent on attendant caregivers to perform all activities of daily living and all instrumental activities of daily living. After living successfully in the community for many years, in February 2004, [redacted] entered the Mississippi Methodist Specialty Care Center, a nursing facility in Jackson, Mississippi, because his live-in caregiver suffered a stroke and was no longer able to assist him. In July 2004, [redacted] was found eligible for Mississippi's Traumatic Brain Injury/Spinal Cord Injury (TBI/SCI) Waiver program.

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[1] *Olmstead v. L.C.*, 527 U.S. 581 (1999), held that unjustified institutionalization is a form of discrimination under the "integration mandate" of the Americans with Disabilities Act. Subsequent cases have established that individuals at risk of institutionalization may bring a complaint under the Americans with Disabilities Act to enforce their right to live in the most integrated setting appropriate to them. *Fisher v. Oklahoma Health Care Auth.*, 335 F.3d 1175, 1182 (10th Cir. 2003); *Brantley v. Maxwell-Jolly*, 2009 WL 2941519 (N.D. Cal. September 10, 2009).

The TBI/SCI waiver is authorized under §1915(c) of the Social Security Act and is administered by the MDM and operated by the MDRS. The waiver provides services to Medicaid beneficiaries who, but for the provision of such services, would require the level of care found in a nursing facility. Eligibility for the waiver is limited to people with traumatic brain injuries and spinal cord injuries. Additionally, to participate in the waiver, individuals must be certified as medically stable by their physician. Medical stability is defined by the State as the absence of the following: "an active, life threatening condition (e.g. sepsis, respiratory, or other condition requiring systematic therapeutic measures), intravenous drip to control or support blood pressure, or intracranial pressure or arterial monitoring." Individuals must also meet Medicaid income limits equal to 300% of the Federal Benefit Rate.

The TBI/SCI waiver furnishes the following services to eligible participants: attendant care services, case management, respite, environmental accessibility adaptations, specialized medical equipment and supplies, and transition assistance services. The waiver application submitted by Mississippi to CMS defines the service at issue in this complaint, attendant care services:

> Attendant Care Services are provided to meet daily living needs to ensure adequate support for optimal functioning at home or in the community, but only in non-institutional settings. Attendant Care Services may include: (a) support for activities of daily living such as but not limited to, bathing (sponge, tub), personal grooming and dressing, personal hygiene, toileting, transferring, and assisting with ambulation; (b) assistance with housekeeping that is directly related to the participant's disability and which is necessary for the health and well-being of the participant such as, but not limited to, changing bed linens, straightening area used by the participant, doing the personal laundry of the participant, preparation of meals for the participant, cleaning the participant's equipment such as wheelchairs or walkers rather than the participant's family; (c) food shopping, meal preparation and assistance with eating, but does not include the cost of the meals themselves; (d) support for community participation by accompanying and assisting the participant as necessary to access community resources; participate in community activities; including appointments, shopping, and community recreation/leisure resources, and socialization opportunities, but does not include the price of the activities themselves.
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> Attendant Care Services are non-medical, hands-on care of both a supportive and health related nature. The provision of attendant care services does not entail hands-on nursing care. This service is provided in accordance with a therapeutic goal in the plan of care, and is not purely diversional in nature.

The evidence shows that since his initial eligibility approval for the waiver, has consistently requested additional attendant care services. In fact, his initial Home and Community-Based Waiver Plan of Care, developed by two DMRS counselors, indicated that requested and needed 24 hours of attendant care services, 7 days a week. This Plan of Care ("POC") was signed by and two MDRS case managers on July 22, 2004. Prior to discharge from the facility, the POC was changed to authorize only18 hours of attendant care services, 7 days a week.

was discharged from the nursing facility in August 2004 with 18 hours per day/7 days a week of attendant care services provided by the TBI/SCI waiver. The State's independent living center, LIFE (Living is For Everyone) voluntarily provided additional hours of attendant care support upon his discharge. After several months, LIFE was no longer able to provide with the additional attendant care services, and requested additional attendant care services under the TBI/SCI waiver. This request was denied by MDM, and asked for a review of the decision.

First Administrative Appeal:

MDM obtained an outside physician, Dr. to review request. On April 17, 2005, Dr. submitted a written report (discussed below) that concluded that additional attendant care hours would not be necessary if the hours without care coincided with time periods when was self-sufficient through the use of assistive technology. Accordingly, MDM denied request on April 25, 2005 and referred him to a specialist to obtain "assistive technology to allow to remain in a community setting." formally appealed this decision, and a hearing was held on August 17 and September 21, 2005. To support his appeal, submitted into the hearing record signed statements from several of his treating physicians and the Director of Nursing from the nursing facility in which he formerly resided (Mississippi Methodist Specialty Care Center). The medical professionals' statements detailed physical condition and need for additional attendant care services. Specifically, the statements noted need for additional hours of attendant care services to address such issues as: (1) care to prevent a condition called explained below; (2) Regular turning and pressure relief to prevent decubitus ulcers; and (3) assistance with feeding and hydration to prevent hypoglycemia, urinary tract infections, and dehydration.

Of primary concern to treating professionals, during this administrative hearing and throughout the time he has been living in the community, is his high risk for ("AD"). AD is a potentially life threatening condition

pressure that can lead to stroke and possibly death, if not treated. treating professionals have stated that in case, AD is mainly the result of a clogged tube, As the Director of Nursing at Methodist Specialty Care noted in her written statement submitted during the administrative appeal: "The diversion constantly produced

which at times could obstruct flow thus possibly causing a . If flow is not resumed, uncontrolled hypertension could occur." His tube can also become obstructed if it twists due to a change in body position. The medical professionals also indicated that the blockages of the can be easily fixed by an attendant.

Not only did the treating professionals document the real risk of based on their knowledge of past history of this condition, his attorney also submitted emergency medical reports from 2004 and 2005 documenting times he had called 911 to deal with issues such as overheating, breathing problems, and high blood pressure due to a clog in his The State's own physician, who reviewed these documents, characterized several of these incidents as "secondary to

On October 13, 2005, an agency hearing officer upheld the agency's decision to deny the additional attendant care hours. In the "Facts Presented" section of the decision, the hearing officer noted that ' asserted the need for 24 hour care as necessary for sustaining his life since his [bag could become blocked thereby causing an onset of The hearing officer did not mention the opinions of s treating professionals in the decision, and instead appeared to rely on the April 17, 2005, report by Dr. Dr. did not examine in person and noted that he had no "actual details as to the client's functional abilities or equipment he currently has and is able to use." Rather, he reviewed documents and records submitted to him by MDM or MDRS, including MDRS case notes, case management notes, the statement from the Director of Nursing at Methodist Specialty Care Center, and 911 emergency records submitted during the hearing. Dr. conclusion that could be adequately served with 18 attendant care hours per day was premised on the assumption that he could obtain limited self-sufficiency with the help of assistive technology, such as a wheelchair that provided pressure relief, adaptive utensils for feeding, and other assistive equipment that would allow him to control the thermostat, and initiate 911 calling. Although attorney disputed many of Dr. findings in a letter to the hearing officer,[2] the hearing officer relied on Dr. recommendation that the 18 hours of care that was receiving was adequate and that the attendant hours could be staggered to meet his needs. The hearing officer also noted "benefits of assistive technology" in upholding the agency's decision to deny the increase in attendant care hours.

Since the 2005 administrative decision that upheld the agencies' denial of additional attendant care hours, has regularly asked for additional attendant care hours

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[2] attorney disputed many of the conclusions of this physician in a letter to the hearing officer dated September 28, 2005, including:

conclusion that he may be able to use adaptive utensils for feeding (he cannot; he is totally dependent for feeding).

during his quarterly reviews with his MDRS counselor. Each time, his requests have not been addressed in the Plans of Care that were developed. Moreover, the Plans of Care and Preadmission Screening Application for Long Term Care Re-Certification Tools that OCR was provided do not even note request for additional hours. Some of these Tools include inaccuracies (e.g., the PAS dated June 5, 2009, states that has paraplegia instead of quadriplegia; this same Tool does not indicate that requires care or turning, repositioning, and range of motion exercises). These inaccuracies and the fact that the tools do not indicate his request for more hours and problems with his assistive technology suggest that the reviews are perfunctory in nature and do not consistently provide a genuine re-evaluation of his needs.

Second Administrative Appeal:

In a letter dated April 25, 2009, attorneys again formally requested an increase in attendant care services through the TBI/SCI waiver. The request included a letter from treating professional, Dr. supporting the request and explaining why the increase in service was medically necessary. Consistent with the treating professionals' statements submitted during the first administrative appeal, Dr. April 20, 2009, letter notes that the lack of attendants for six hours a day "places at risk for serious medical complications." Dr. explained that remained totally dependent on others to perform all ADLs and IADLs, including eating snacks to maintain proper blood sugar levels, frequently hydrating to prevent urinary tract infections, and repositioning every two hours while in bed or his wheelchair. Dr. also noted risk for decubiti, blood clots, muscle contractures, and due to the level of his spinal cord injury. Dr. was particularly concerned about noting that has in fact experienced "numerous episodes of , resulting in serious hypertension" and Dr. concluded:

> A personal care provider can attend to these issues to avoid medical complications and to ensure continued well-being, however, there is no way to predict when these episodes might occur. A gap in personal assistance over a period of 6 hours each day, however scheduled, places at unnecessary risk of potentially life-threatening complications.[5]

[4] Dr. recently reiterated these concerns to OCR. In particular, he believes that due to susceptibility to AD, he should be left unattended no more than one hour at a time but that his strong preference is for 24/7 attendant care. He noted that AD can become dangerous quickly and there is no way to predict when it will occur.

This formal request for additional attendant care hours was denied by MDRS on June 2, 2009. The Notice of Action from MDRS informing [redacted] of the decision included an attachment that noted:

> [[redacted] has] suffered complications related to the clogging of [his] [redacted] drainage tube and [has] sought emergency medical care through calling 911. Supporting statements were made by the attendant, [redacted], confirming that he has found [[redacted] to suffer these episodes.

MDRS pointed out that [redacted] had made the same request previously and the attachment to the Notice of Action stated:

> No evidence of significant medical changes have been submitted to justify additional hours needed. Furthermore, the time logs do not reflect that any tasks/needs are going unmet. . . . The TBI/SCI Waiver clearly explains that the provision of Attendant Care Services are non-medical, hands-on care of both a supportive and health related nature. The service is provided in accordance with a therapeutic goal in the plan of care, and is not purely diversional in nature. . . . To have someone present, but not performing a task with a therapeutic goal would be considered purely diversional.

On June 30, 2009, [redacted] attorney requested a local Medicaid hearing to challenge the denial of additional attendant care services and to show that the additional hours of care he was requesting could not be characterized as "diversional." A hearing was held on July 14, 2009. During the hearing, evidence to support his request for additional attendant care hours was presented, including information about the need for constant [redacted] observation and care to avoid [redacted] and his inability to control the thermostat in his apartment, which can lead to overheating and dehydration (attempts to use a voice activated environmental control system have been unsuccessful).

Following the hearing, in an August 12, 2009, letter, the hearing officer denied the request for an increase in attendant care services. No factual basis for the determination was included in the letter.

Complaint to OCR and the State's Position:

Following the September 18, 2009, Complaint to OCR alleging that MDRS and MDM refused to provide [redacted] with the sufficient amount of personal care services under the TBI/SCI waiver in violation of Title II and Section 504, OCR issued a Letter of Notification on December 7, 2009, informing MDRS that the complaint had been filed. On January 12, 2010, OCR issued a similar Letter of Notification to MDM. A Data Request was attached to both Letters of Notification seeking information on the TBI/SCI Waiver and the agencies' response to the complaint's allegations.

MDRS responded to OCR in a letter dated January 25, 2010. MDRS denied any acts of discrimination against and explained that all Plans of Care under the waiver are individualized to address the needs of the consumer. Specifically, MDRS noted that Plan of Care was developed by his case management team at the time of transition from the nursing facility in 2004 and is continuously reviewed and updated to address changes in his needs. MDRS further noted in its response the following:

> receives more attendant care services than any other waiver participant with the same or similar medical condition. Please note that attendant care services must be provided in accordance with a therapeutic goal in the Plan of Care. These services must not be purely diversional in nature.

MDRS concluded that "at present, there are no indications that a change is needed with regard to his POC." MDRS did not detail in this letter why the additional hours that is requesting are not "in accordance with a therapeutic goal in the Plan of Care" or why they are considered "diversional."

On March 30, 2010, MDM responded in a letter to OCR that had not contacted that agency in 2009 or 2010 specifically for an increase in his attendant care hours, but that MDM was notified by MDRS in June 2009 that MDRS had denied request for increased attendant care hours. MDM noted that is only one of two waiver participants receiving 18 hours per day of attendant care services. MDM did not respond specifically to the allegation of disability discrimination.[4]

During the course of the investigation of . complaint, OCR conducted several interviews, including interviews of a current treating physician, his attendants, himself, and an independent medical professional experienced in the care of persons with quadriplegia. OCR obtained facts during those interviews and through its review of extensive documentation submitted by attorney and MDRS that indicate that is at risk of institutionalization. The evidence shows that the State failed to modify his Plan of Care to provide the additional services that would be effective to ensure that he is not at risk of institutionalization.

Specifically, Dr. treating professional for approximately three years, told OCR that risk of developing serious complications from is grave and potentially life threatening if his tube is not quickly unclogged when it does not drain properly. Dr. suggests that because has a history of experiencing the symptoms of he should not be left unattended for more than an hour at a time. Dr. explained

[4] Because MDRS, not MDM, administers the waiver, OCR's investigation focused on the role MDRS played in refusing to consider the request for additional hours. However, as Medicaid agency for the state, MDM is equally responsible for any failure by MDRS to comply with the ADA and Section 504.

that [redacted] is unpredictable, in that you do not know when it will occur, and it can become dangerous very quickly.

[redacted] attendants have stated that when they arrive for work (after [redacted] has been left unattended for approximately three and a half hours or two and a half hours, depending on the shift) they frequently find [redacted] experiencing symptoms of [redacted]. One attendant describes [redacted] state during these episodes as being in "crisis mode," meaning [redacted] is sweating profusely, experiencing shortness of breath and complaining of a severe headache, indicating a rise in blood pressure and the onset of [redacted]. One attendant estimates that it happens at least one time per each of the attendant's four-day work weeks, and sometimes even more frequently.

When the attendants find [redacted] in "crisis mode," they immediately determine why his [redacted] tube is not allowing [redacted] The attendants know that the improper draining of the [redacted] causes the symptoms of [redacted] If the [redacted] is twisted or out of position, the attendants reposition it or shake it to get the [redacted] flowing properly again; other times the [redacted] becomes clogged due to excess mucous that must be cleaned. According to the attendants, once the urine begins to flow normally, [redacted] symptoms of a [redacted] subside.

One attendant described a recent occurrence of AD on June 21, 2010. When the attendant came to work, [redacted] told him to immediately check his [redacted] because he was in the middle to latter stages of [redacted] [redacted] was sweating and had a severe headache. Once the [redacted] bag was properly draining [redacted] his symptoms started to go away.

Two attendants report routinely and voluntarily coming into work early out of concern for [redacted] well-being. Several times during the past year, [redacted] has called two of his attendants at home to come in early to assist him when he felt the symptoms of dysreflexia advancing. One attendant said that [redacted] called recently and needed help because he was experiencing shortness of breath. The attendant was unable to come in early due to family issues, however, and [redacted] had to call 911 to address the problem.

[redacted] has repeatedly asked MDRS representatives during his quarterly reviews to modify his current Plan of Care by providing more attendant care hours. Most recently, he asked for additional hours during his June 2010 review. According to [redacted] attorney, the DRS representatives conducting the review did not respond to this request. One attendant confirmed that he has witnessed [redacted] repeatedly telling the case workers about his need for additional personal care services during the reviews, but that their response has been that they can do nothing about it.

In an effort to more fully understand the State's response to [redacted] complaint set out in the January 25, 2010, letter from MDRS and the March 30, 2010, letter from MDM, OCR spoke by telephone several times with MDRS Deputy Director Sheila C. Browning and members of MDRS staff. One of these phone conferences occurred on May 3, 2010, after OCR was informed by [redacted] attorney that [redacted] had experienced a recent incident of AD when he was unattended.[5] During this phone conversation, MDRS indicated that it had no documentation that [redacted] had ever experienced AD. Further, MDRS re-stated the TBI/SCI waiver's requirement that attendant care services must not be "diversional" in nature. MDRS also mentioned that [redacted] should not require attendants when he is asleep, and that the State had provided [redacted] with assistive technology to aid in his independent living, including an environmental control unit to control the temperature of his apartment and a mattress that shifts his weight while he is in bed. MDRS noted that in order to receive additional services under the waiver, a consumer must point to what specific activity of daily living was not being performed during the unattended hours.

Although this information had previously been provided to the State numerous times by [redacted] and his attorneys, both in the administrative hearings and through [redacted] repeated requests for additional hours, OCR e-mailed Ms. Browning on May 14, 2010, attaching a document that explained in detail what OCR's investigation had revealed regarding [redacted] need for additional attendant care hours. Largely quoting treating professionals' opinions and 911 reports, OCR documented [redacted] need for additional attendant care hours for services including: (1) [redacted] care to prevent the onset of [redacted] [redacted]; (2) Turning [redacted] body while in bed and re-positioning his body while he is in the wheelchair to prevent skin breakdown; (3) Bowel program cleanup for hygiene and to prevent skin breakdown; (4) Hydration assistance to prevent urinary tract infections; (5) Nutritional and feeding assistance to avoid hypoglycemic episodes; and (6) Temperature and climate control assistance to prevent the onset of [redacted] [redacted] and dehydration. OCR clarified that the voice activated equipment that was previously provided does not work for [redacted] because of voice fluctuations,[6] that [redacted] needs attendant care when he is asleep (a conclusion made by both [redacted] treating physicians and the state's physician during the administrative hearings), that the pressure-relieving mattress and wheelchair provided to him do not function adequately, and that he has been determined medically stable by MDRS during each of his quarterly assessments. OCR also noted that in addition to

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[5] On April 28, 2010, [redacted] attorney informed OCR via e-mail that [redacted] once again, had experienced the onset of AD while he was left unattended. The attorney reported that he began experiencing symptoms of AD (severe headache that signifies a dangerous rise in blood pressure) at approximately 8:30 p.m. on April 25, 2010, and phoned one of his attendants to come in early to unclog his [redacted] tube, which had become occluded. The attendant arrived approximately 40 minutes later (50 minutes prior to his shift) and simply unclogged the [redacted] equipment, which immediately caused his blood pressure to lower. OCR shared this information with MDRS during the phone conversation on May 3.

[6] Each of his attendants have confirmed to OCR that [redacted] has been unable to use a voice activated environmental control unit since they have been working for him.

calling 911 several times, [redacted] has, at times, called his attendants to come in early when he experiences the initial symptoms of [redacted]

Additionally, OCR explained to DMRS that CMS had clarified that Medicaid law does not prohibit the provision of diversional services and that there is no federal limit on the number of attendant care hours that a state may authorize for an individual. In fact, CMS has approved waivers for up to 24 hours of attendant care in states that have determined that this amount of care is needed for an individual under that waiver.[7] The e-mail concluded by asking Ms. Browning to inform OCR whether MDRS would provide additional attendant care hours, or, in the alternative, evaluate [redacted] in person to determine the number of hours that he requires to remain in the community.

In response to OCR's May 14, 2010 e-mail clarifying the need for additional services, Ms. Browning responded by e-mail on May 27, 2010: "[W]e are unable to increase [redacted] hours of Personal Care Attendant Services based on the information you submitted. Also, a face to face re-evaluation of [redacted] was conducted in March as part of the recertification process, thereby removing the need to conduct another one at this time." Following this e-mail response, OCR reviewed the March re-evaluation MDRS relied on in refusing to conduct another evaluation. The March re-evaluation failed to address [redacted] and the failure of his assistive technology to allow him to be self-dependent at any time. After determining that MDRS's cursory review had not addressed the reasons for [redacted] request for a modification in his Plan of Care, OCR had another phone conference with Ms. Browning on June 4, in which OCR suggested that that MDRS contract with an objective independent medical professional to assess [redacted] need for additional attendant care hours. In a follow-up e-mail on June 7, 2010, OCR once again sent the document that explained [redacted] attendant care needs, noting that the independent assessment would have to address those needs in particular.

On June 16, 2010, Ms. Browning replied in an e-mail that: "[C]ircumventing the established protocol for determining individuals eligible for the Waiver and the appropriate services needed to accomplish their goals is not a viable option. Further, none of the conditions outlined by [redacted] are present conditions nor in the over five (5) years that he has been on the waiver program is there documentation of any of these conditions occurring." In a follow-up conversation with OCR, Ms. Browning clarified that no documentation of the conditions described by OCR ([redacted] etc.) had been produced during his initial or quarterly assessments, that his personal care workers had not reported such a condition, and that there was a general lack of documentation, leading the agency to determine that no assessment was necessary. OCR noted that [redacted] had provided extensive documentation of this problem which was confirmed by the State's own professionals and had raised the need for additional

[7] The TBI/SCI Waiver manual itself states: "There are no pre-determined or fixed limits on the number of services or the number of units of any particular service. (For example – personal care services)." This policy provision was the result of a settlement agreement in a class action lawsuit. *Billy A. v. Jones*, Civil Action No. 3:02CV475WS (S.D. Miss.).

attendant care in his quarterly assessments with no adequate response. Ms. Browning indicated that the State would not conduct any further assessment or adjust [redacted] Plan of Care.

III. Discussion and Analysis

A. [redacted] is a Qualified Individual with a Disability

In order to be protected under the ADA and Section 504, an individual must be a "qualified individual with a disability." An "individual with a disability" is a person who has a physical or mental impairment that substantially limits one or more life activities. 28 C.F.R. § 35.104 and 45 C.F.R. § 84.3(j). The phrase "major life activities" means "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." 28 C.F.R. § 35.104 and 45 C.F.R. § 84.3(j)(2)(ii). The phrase "physical or mental impairment" means "[a]ny physiological disorder or condition . . . affecting one or more of the following body systems: neurological; musculoskeletal . . . respiratory (including speech organs), cardiovascular . . . ." 28 C.F.R. § 35.104 and 45 C.F.R. § 84.3(j)(2)(i). A "qualified individual with a disability" means "an individual who, with or without reasonable modifications to rules, policies, or practices . . . meets the essential eligibility requirements for receipt of services or participation in programs" conducted by a covered entity. 28 C.F.R. § 35.104 and 45 C.F.R. § 84.3(l)(4).

OCR concludes that [redacted] is an "individual with a disability" because the record contains clear medical evidence that he has a physical impairment [redacted] quadriplegia) that substantially limits one or more major life activities (i.e., he requires total assistance with all activities of daily living and all instrumental activities of daily living). Attendant care is a service provided under the TBI/SCI waiver, which is made available by MDM and administered by MDRS. [redacted] meets the essential eligibility requirements for receipt of the TBI/SCI waiver,[8] and is therefore a "qualified individual with a disability."

B. MDM and MDRS Violated Section 504 and Title II of the ADA By Failing to Modify [redacted] Plan of Care Under the TBI/SCI Waiver Program Without Demonstrating that the Modification Would Result in a Fundamental Alteration

The ADA regulations state that a "public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity," 28 C.F.R. § 35.130(b)(7), or cause "undue financial and administrative burdens." 28 C.F.R. § 35.150.

[8] As recently as June 2010 [redacted] has been found eligible for the TBI/SCI waiver during his quarterly assessment by an MDRS case manager.

Section 504 also requires recipients of Federal financial assistance to make reasonable modifications to their existing programs or services to accommodate otherwise qualified persons. *See Southeastern Community College v. Davis*, 442 U.S. 397 (1979); *Alexander v. Choate*, 469 U.S. 287,300 (1985); *Guckensberger v. Boston University*, 974 F. Supp.106, 134 (D. Mass 1997). Accordingly, the State has an obligation to make reasonable modifications to its services and programs to avoid discrimination on the basis of disability.

As described above, OCR's investigation revealed that since he was initially determined eligible for the TBI/SCI waiver in 2004, [redacted] has consistently requested modifications to his Plan of Care to avoid re-institutionalization, both informally during his quarterly reviews with MDRS and formally through letters from his attorney and through at least two administrative appeals. When [redacted] filed his discrimination complaint with OCR, OCR issued its notification letters to the State, wherein the State was once again made aware of [redacted] request for a modification of his Plan of Care under the TBI/SCI waiver program. For the reasons set forth below, OCR concludes that the State is in violation of the reasonable modification requirements of Section 504 and its implementing regulation at 45 C.F.R. § 84.4(a) and Title II of the ADA and its implementing regulation at 28 C.F.R. § 35.130(b)(7).

Under Title II and Section 504, when a public entity receives a request for a reasonable modification, it has a duty to engage in an "interactive process" with the individual with a disability making the requests.[9] As part of that interactive process, the covered entity must gather sufficient information from the disabled individual and qualified experts as needed to determine whether the request is reasonable.[10] The determination of whether a modification is "reasonable" involves a fact-specific, case-by-case inquiry that considers, among other factors, the effectiveness of the modification in light of the nature of the disability in question.[11] The mere speculation that a suggested accommodation is not feasible falls short of the "reasonable accommodation" requirements of the ADA and 504.[12]

In analyzing whether [redacted] requests for additional personal attendant care services would create an undue burden or result in a fundamental alteration, the burden of proving fundamental alteration rests with the covered entity.[13] [redacted] has repeatedly presented a legitimate request to the State for modifications to his Plan of Care that was rooted in clear and credible medical evidence of his history of experiencing AD as well as his ongoing risk of experiencing AD, his need for constant pressure relief, [redacted] care, bowel care, hydration and nutrition assistance, and temperature control, among

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[9] *Vinson v. Thomas*, 288 F.3d 1145, 1154 (9th Cir. 2002).
[10] *Duvall v.County of Kitsap*, 260 F.3d 1124 (9th Cir. 2001).
[11] *See Messier v. Southbury Training School*, 562 F. Supp.2d 294 (D. Conn. 2008); Staron v. McDonald's Corp., 51 F.3d 353, 356 (2d Cir.1995).
[12] *See Wong v. Regents of University of California*, 192 F.3d 807 (9th Cir. 1999).
[13] *See Martin v. Taft*, 222 F. Supp.2d 940 (S.D. Ohio 2002) (citing *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 604 (1999) and 28 C.F.R. 35.130(b)(7)).

other things. Since 2005, MDRS and MDM have refused to accommodate [redacted] request without meeting their burden to show that the request was unreasonable or would result in a fundamental alteration.

Since MDM's refusal in 2005 to provide [redacted] with additional attendant care hours, [redacted] repeatedly continued his requests and notified MDRS representatives that his assistive technology did not allow him to conduct his daily activities independently. MDRS refused to address [redacted] requests for modification without explanation. In 2009, in response to [redacted] formal request for a modification to his Plan of Care, MDRS stated that [redacted] had made this request previously and "no evidence of significant medical changes have been submitted to justify additional hours…."

MDRS's 2009 response ignored the basis of MDM's decision in 2005, which was premised on the assumption that assistive technology could allow [redacted] to conduct his daily activities independently, and during those times [redacted] could be without attendant care. As the Medical Director of Health Systems of Mississippi, MDM's Utilization Management and Quality Improvement contractor, noted at that time, "Dr. [redacted] does not believe the six hours at issue are medically necessary *if* the absence of personal attendant services can be scheduled to coincide with the beneficiary's daily activities."[14] As noted above, the assistive technology provided to [redacted] including the voice-activated thermostat, has not been able to meet his needs when his personal attendants are absent. Moreover, he has noted his inability to independently obtain pressure relief in his wheelchair, eat or drink by himself, all of which Dr. [redacted] report assumed he would be able to do independently with assistive technology during the time periods he was without personal attendants.

More recently, OCR presented information regarding [redacted] need for additional attendant care services to MDRS during the course of its investigation. Despite the credible information that has been provided to the State regarding [redacted] needs for additional attendant care hours, it has not performed an adequate individualized assessment to determine whether his request for a modification of his Plan of Care is reasonable. The State also rejected OCR's recommendation that an independent evaluation [redacted] needs be conducted. The State pointed out that [redacted] is evaluated quarterly by his case managers. However, OCR finds that the quarterly assessments performed by his case managers have been inadequate to address his requests for additional services and that the opinions of his treating physicians (that he requires additional attendant care) carry more weight than these cursory assessments.[15] Further, OCR's review of the past administrative proceedings found that they ignored key evidence presented by [redacted] treating professionals that [redacted] needs additional hours of attendant care services because he is at risk of the potentially life threatening condition of [redacted], among other conditions. The State has repeatedly taken the position that attendant care services must not be purely diversional. However,

[14] See April 19, 2005 letter from Robert P N Shearin, M.D., Medical Director of Health Systems of Mississippi, to Mike Gallarno (emphasis in original).
[15] *See, Knowles v. Horn*, 2010 WL 517591 (N.D. Tex.).

OCR previously notified the State that CMS clarified that Medicaid law does not prohibit the provision of diversional services and that there is no federal limit on the number of attendant care hours that a state may authorize for an individual. In fact, CMS has approved waivers for up to 24 hours of attendant care in states that have determined that this amount of care is needed for an individual under a waiver program.

The evidence gathered by OCR establishes that the State has impermissibly refused to modify [redacted] Plan of Care under the TBI/SCI waiver program by providing him with additional care hours. The State has not argued that the modification requested by [redacted] could not be reasonably accommodated under its existing TBI/SCI waiver or that it would fundamentally alter the nature of the program. Even if the State were to assert a fundamental alteration defense, it is clear that in this case the State could accommodate [redacted] request for additional care hours under its existing TBI/SCI waiver program because there is no federal limit on the number of attendant care hours it can authorize. The fact that [redacted] currently receives more attendant care hours than any other waiver participant with the same or similar condition is not an acceptable justification for the State's failure to provide a reasonable modification to his Plan of Care.

As noted above, under the ADA and Section 504, a State has an obligation to make reasonable modifications to their existing programs or services to avoid discrimination against individuals with disabilities, unless it can demonstrate that making the modification would fundamentally alter the nature of the service or program. The facts show that the State has refused to consider seriously [redacted] repeated requests for modifications to his Plan or Care. Although [redacted] has repeatedly informed his MDRS case workers of his need for additional attendant care services during his quarterly scheduled in-home visits, the State has refused to conduct a comprehensive assessment of [redacted] condition to determine whether his requested modification to his Plan of Care would be reasonable in light of the nature of his particular disability. Also, the State has not presented any evidence that demonstrates that the modification requested by [redacted] is not necessary to avoid discrimination on the basis of disability, or that it would result in a fundamental alteration of the services provided under the TBI/SCI program. As a result of the State's actions, [redacted] has been denied an equal opportunity to benefit from the attendant care services available under the TBI/SCI waiver program.

For the reasons stated above, OCR finds MDM and MDRS in violation of the reasonable modification regulatory provisions established under Title II of the ADA, 28 C.F.R. § 35.130 (b) (7), and Section 504, 45 C.F.R. § 84.4(a), for failing to consider seriously [redacted] legitimate requests for a modification to his Plan of Care and for failing to provide any evidence that the requested modification would result in a fundamental alteration of the TBI/SCI program. Also, as discussed below, OCR determined that the State's refusal to modify [redacted] Plan of Care under the waiver program places him at risk of unnecessary institutionalization.

C. MDM's and MDRS's Failure to Modify [redacted] Plan of Care under the TBI/SCI Waiver Program Places Him At Risk of Unnecessary Institutionalization

Under both Title II of the ADA and Section 504, covered entities must administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. 28 C.F.R. § 35.130(d); 45 C.F.R. § 84.4(b)(2). The "most integrated setting" is a "setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible." *See* 28 C.F.R. Part 35, App. A. In *Olmstead v. L.C.*, 527 U.S. 581 (1999), the Supreme Court interpreted the integration regulation established under Title II of the ADA and Section 504 to prohibit "unjustified institutional isolation of persons with disabilities." Although the plaintiffs in *Olmstead* were individuals confined in state institutions who wanted to live in the community, the Court's ruling was broader than the facts in that case. The Court explained that its holding "reflects two evident judgments." 527 U.S. at 600.

> First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options . . . and cultural enrichments.

Id at 601. These concerns exist in situations where individuals seek to avoid unnecessary institutionalization, as well as in situations where persons confined to an institution seek to return to their communities.

The complaint filed with OCR on behalf of [redacted]. [redacted] alleges that the State's failure to approve his request for additional personal care hours places him at risk of institutionalization. [redacted] treating professionals and the state's professionals concur that he is appropriate for community-based services and can be served in the community with adequate supports. Courts have held that the risk of institutionalization is sufficient to demonstrate a violation of the integration requirements of Title II of the ADA and Section 504. *See Fisher*, *supra.*, at 1182; *Brantley*, *supra.*, at 1161; *Makin v. Hawaii*, 114 F. Supp. 2d 1017, 1034 (D. Haw. 1999) (Plaintiffs residing at home could challenge the state's administration of home and community-based services offered through the state's Medicaid program). In the instant case, the State's failure to modify [redacted] Plan of Care by providing him with additional personal attendant care hours places him at risk of unnecessary institutionalization. *See V.L. v. Wagner*, 669 F. Supp. 2d 1106, 1119 (N.D. Cal. 2009) (Plaintiffs currently residing in community settings may assert ADA integration claims to challenge state actions that give rise to a risk of unnecessary institutionalization); *Ball v. Rodgers*, No. 00-cv-67, 2009 WL 1395423, at * 5 (D. Arizona April 24, 2009) (State violated Title II integration mandate because its failure to provide the plaintiffs with the necessary services threatened them with institutionalization).

The evidence shows that has repeatedly requested a modification to his Plan of Care under the TBI/SCI waiver program that would increase his number of attendant care hours. In the opinion of treating physician, he needs additional hours of attendant care services to address such issues as: (1) care to prevent (AD), a potentially life threatening condition suffered by people with spinal cord injuries; (2) regular turning and pressure relief to prevent decubitus ulcers; and (3) assistance with feeding and hydration to prevent hypoglycemia, urinary tract infections, and dehydration. The primary concern treating physician is the likelihood of episodes of AD resulting from a clogged tube which diverts urine from bladder to a bag outside of his body. has provided documentation from treating professionals regarding the real risks of AD based on their knowledge of his past history of this condition. Most recently, treating physician, Dr. reiterated his ongoing concern that due to susceptibility to AD he should not be left unattended for more than one hour at a time. Under his current Plan of Care, is left unattended for 6 hours a day – once for 2.5 hours and another time for 3.5 hours.

When the State upheld the decision to provide with only 18 hours of attendant care services, it based that decision primarily on the conclusions reached by Dr. after his review medical records. Even though Dr. acknowledged that he had no actual details as to functional abilities, he nonetheless recommended 18 hours of attendant care services with two unattended time blocks. This recommendation was premised upon the assumption that assistive technology would allow the opportunity to conduct daily activities independently, such as pressure relief, thermostat control, eating and drinking, and calling 911. The State maintains that has been provided with assistive technology to aid in his independent living, including an environmental control unit to the temperature of his apartment, a specialized wheelchair and a mattress that allows him to shift his weight while he is asleep. previously notified the State regarding problems that he has experienced with his assistive technology. OCR has also attempted to clarify to the State that the voice activated equipment that has been provided with does not function properly because of his voice fluctuations. To date, OCR has not been notified of any steps that the State has taken to address these problems.

The State has attempted to justify its repeated refusals to approve request for additional hours on several grounds. First, the State contends that has not provided sufficient documentation of his need for additional care hours. However, evidence gathered by OCR clearly contradicts that contention. In addition, the State contends that the 18 hours of care that currently receives are adequate because he can stagger those hours with two three hour unattended time blocks to meet his needs. Statements provided to OCR by personal care attendants confirm that they have recently found him suffering from episodes of AD when they reported for their shifts. Both and OCR have also informed the State that on several occasions he has been forced to seek emergency medical care for complications related to the clogging of his drainage tube through 911. Most recently, called

911 in June 2010 when his attendant was unable to come to his home and assist him when he was experiencing shortness of breath. Two personal care attendants also confirmed that they typically arrive at [redacted] house earlier than scheduled out of concern for his well-being. [redacted] reliance on 911 calls to unclog his [redacted] or going to the hospital is a costly way to remedy his episodes of AD. The facts obtained by OCR clearly undermine the State's contention that 18 hours of attendant care services along with his current assistive technology adequately meet [redacted] in-home needs.

As stated above, the unjustified institutional placements of individuals who can handle and benefit from community settings has been recognized as a form of discrimination that is prohibited under Title II of the ADA and Section 504. Evidence obtained by OCR establishes that [redacted] has been able to handle and benefit from living in a community setting and interacting with nondisabled individuals. While living at home, [redacted] has been able to maintain social contacts with relatives and friends, go to restaurants, run errands, such as shopping and paying bills, and enjoy outdoor activities like sitting in the park. If [redacted] were forced unnecessarily to move to a nursing home solely to receive additional personal attendant care services that he needs to remain in the community, this would be precisely the type of disability discrimination that has been explicitly prohibited by the Supreme Court in *Olmstead*.

OCR's investigation has found sufficient evidence to substantiate that [redacted] current Plan of Care is not adequately addressing his in-home needs. In addition, the State has not presented any evidence that the approval of [redacted] request for additional attendant care services would require a fundamental alteration of the TBI/SCI waiver program. In the absence of such evidence, the State's refusal to grant [redacted] request for reasonable accommodation places him at risk of institutionalization in violation of the integration requirement of Title II of the ADA and Section 504 codified respectively at 28 C.F.R. § 35.130(d) and 45 C.F.R. § 45 C.F.R. 84.4(b)(2).

IV. Conclusion and Remedy

OCR finds that MDM and MDRS have failed to comply with their obligations under Title II of the ADA and Section 504 to make reasonable modifications to policy and procedures when necessary to avoid discrimination on the basis of disability. Also, MDM's and MDRS's failure to approve [redacted] request for a reasonable modification to his Plan of Care under the TBI/SCI waiver program places him at risk of institutionalization in violation of the integration requirement established under Title II of the ADA and Section 504 of the Rehabilitation Act.

The State has **thirty (30) calendar days** from the date of this letter to provide [redacted] with the necessary attendant care hours or otherwise modify his Plan of Care to ensure that he is not at-risk of institutionalization, in violation of the integration mandate of the ADA. Please contact my office within seven (7) days of receiving this letter to inform us of your plan to accomplish the required remedy within the time frame noted above. Please note that pursuant to authorities cited above OCR is required to seek voluntary,

informal resolution of findings of non-compliance. To that end, please be advised that OCR stands ready to provide technical assistance and to discuss informally voluntary measures the State should institute to remedy the violations discussed above.

If we are unable to achieve an acceptable informal resolution of this matter within the time specified above, you should note that OCR will commence formal steps to enforce compliance as provided under the regulations implementing Title II and Section 504.

Advisements

COMPLAINANT'S RIGHT TO FILE A CIVIL ACTION

General Notice

The complainant may have the right to file a civil action to remedy discrimination by a recipient of Federal financial assistance or other covered entity.

The complainant may wish to consult an attorney about his/her right to pursue a private cause of action, any applicable statute of limitations, and other relevant considerations.

PROHIBITION AGAINST RETALIATION

The complainant has the right not to be intimidated, threatened, coerced by a recipient/covered entity or other person because he or she has made a complaint, testified, assisted, or participated in any manner in an investigation, proceeding, or hearing held in connection with a complaint.

DISCLOSURE OF RECORDS

Under the Freedom of Information Act, it may be necessary to release this document and related correspondence and records upon request. In the event OCR receives such a request, we will seek to protect, to the extent provided by law, personal information which, if released, would constitute an unwarranted invasion of privacy.

If you have any questions, or would like to discuss this matter further, you may contact me by phone at: (404) 562.7859, or via email at: roosevelt.freeman@hhs.gov.

Sincerely yours,

Roosevelt Freeman
Regional Manager