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February 3, 2014

Via Electronic Mail, KarenR@drcnh.org
Disability Rights Center, Inc.
18 Low Avenue
Concord, NH 03301-4971

RE: Investigation Report Regarding Death of Mr. [redacted]

Dear Ms. Rosenberg:

This letter is in response to your report, dated January 6, 2014, regarding the death of [redacted] while he was a resident at Lakeview NeuroRehabilitation Center, Inc. ("Lakeview"). We value your having provided your perceptions and concerns regarding this event with us as part of Lakeview's continuous quality improvement efforts.

Mr. [redacted]'s death was a tragic event, one which was deeply saddening for the staff and clinicians working with him. It has left a lasting impression on Lakeview staff and leadership at all levels of the organization. Immediately following Mr. [redacted]'s death, our quality assurance department conducted an extensive internal investigation to determine root causes and contributing factors. We concur without hesitation that aspects of Mr. [redacted]'s stay at Lakeview were inconsistent with Lakeview's values of dignity and respect for those we serve, and to which we expect all Lakeview employees adhere. Likewise, our review indicates that for a period of time upon arrival at Lakeview, case management, communication and coordination of care did not reflect our expectations. Realization of these issues, and exploration of their causes and contributing factors, has lead to a number of quality improvement initiatives with processes implemented including:

- A more extensive review of pre-admission materials and treatment history during the initial evaluation period following admission, to assure that our treatment plan takes into account all available historical information;

- A pre-admission conference with the NH area agency team for NH area agency referrals and admissions;

- A more systematized review of case management documentation and QA to ensure compliance with monthly reporting and audit standards;

- Establishment of a protocol that requires the primary nurse or designee to retrieve and review active Input/Output tracking sheets daily and to communicate findings as necessary (including documentation on monthly health summaries);

- Weekly review and revision of Level of Supervision (LOS) tracking sheets by the Risk Management Committee;

- Training of overnight Shift Supervisors to review and assure compliance with documentation requirements of direct care staff;

- Standardized code response protocols (currently in review/revision with our Safety committee) including "Code BLUE" response protocol;

- Ambu-bags in every client building;

- Emergency response bags and secured oxygen tanks in multiple locations on campus;

- Review and revision of policies and procedures related to suicide risk assessment, documentation and management, and training of relevant staff to assure adherence to these policies;

- Training for all direct care staff on responding to medical events (suspected or witnessed);

- A comprehensive review and realignment of staffing needs for all units and implementation of a system to routinely review the need for changes to staffing;

- Assessment of our communication systems for managing staff deployment and the acquisition of additional resources to improve communication among staff and supervisors;

- The collaborative development, with representatives from the Bureau of Elderly and Adult Services (BEAS), of current training materials regarding identification and mandated reporting of abuse, neglect and exploitation. This training was integrated into the New-Staff Orientation curriculum in January 2013 and into the mandatory quarterly training sessions for all staff in February 2013.

Lakeview has also continued to evolve its leadership and supervisory structure, and to improve the depth of knowledge and experience of its management and staff in the many months since Mr. [redacted]'s death. These changes are part of our overall quality assurance initiatives and demonstrate the ways in which we have made strides in the improvement of service delivery. Changes include:

- Addition of a licensed, doctoral level Clinical Director position to work in collaboration with the Administrative Director, providing dual leadership for the day-to-day operations of the facility. This position was filled by an experienced clinician,

manager and trainer with a demonstrated track record of facilitating quality improvements and systems change in larger hospital settings;

- New doctoral level QA/QI Director recruited with in-depth rehabilitation/disability knowledge (Nationally Certified Rehabilitation Counselor);

- Director of Youth Programs recruited at a doctoral level (School Psychologist with clinical and neuropsychology training) with extensive experience in behavioral health, trauma care and youth development;

- Addition of certified EMTs on evening, overnight and weekend shifts as part of the on-unit management and emergency response system and in conjunction with Huggins Hospital;

- Relocation of Case Managers' offices to join other professional staff in on-unit office space to increase opportunities for face-to-face interaction with program participants, direct care staff and clinical team members;

- On-unit Direct Care Management presence doubled across all awake shifts (one for each program).

In addition to informing you of the changes that Lakeview has undergone since [redacted] of 2012, we also wish to provide comments regarding factual inaccuracies contained in your January 6, 2014 report. Please see referenced sections (*in italics*) and according corrections below. These factual corrections require revision to other sections of the report where these specific inaccuracies are repeated or referenced. Our hope is that these corrections will be incorporated into your report accordingly.

[redacted] *had a seizure disorder which, prior to his admission to Lakeview, had been successfully managed with medication (p. 1, 2nd paragraph 4th sentence).*

- Mr. [redacted] had intractable seizures – defined as seizures that fail to respond to at least two appropriate anti-seizure medications – that generally occur once or twice per month (non-Lakeview Neuropsychological evaluation completed on [redacted]. Mr. [redacted] had two significant seizures during the month of [redacted] during his 72-day tenure at Lakeview. Neurological assessment following his 2nd seizure reflected levels of Depakote above therapeutic levels and within range levels of Zonisimide. Given his history of Depakote use, the decision was made by his board-certified neurologist not to adjust the Depakote levels, but rather to raise the Zonisimide dose to 400mg, bringing him even closer to the maximum dose of 600mg. This pre-admission record reporting intractable seizures, and Mr. [redacted]'s Lakeview seizure activity, indicate that Mr. [redacted]s seizure activity was not "successfully managed" prior to admission.

Reports alleged that Lakeview failed to provide appropriate medical and/or behavioral interventions to address [redacted]'s physical, emotional and behavioral issues (p. 1, 2nd paragraph 5th sentence).

- According to medical records, during his 72 day tenure at Lakeview, Mr. [redacted] met with or was reviewed by a member of the Lakeview treatment team on at least 40 occasions in order to address a myriad of longstanding and complex physical, emotional and behavioral issues.

- With regard to seizures, Mr. [redacted] had 2 seizures during his time at Lakeview. Appropriate follow-up occurred in both instances, including transfer to an emergency department following each seizure, and review and adjustment of medication by a board-certified neurologist following his seizure activity. Levels of seizure medication remained therapeutic throughout his stay.

- Mr. [redacted]s weight was another issue of concern. Records reflect that Mr. [redacted] had a history of eating issues, at times being a "picky" eater and consuming minimal amounts, and at other times over-eating uncontrollably. According to available pre-admission records, the year prior to his admission to Lakeview, in [redacted] of [redacted], Mr. [redacted] weighed over 300 pounds, and his providers expressed great concern over his insatiable appetite and eating patterns, considered to be the result of psychotropic medication. Mr. [redacted] arrived at Lakeview weighing 269 lbs, which is considered obese for a man of his height. The goal was to help Mr. [redacted] lose weight, with an eventual goal of 205 pounds. When it was noted that his appetite was poor and his weight loss was occurring at an accelerated rate, his treatment team made modifications to his diet and behavior plan to encourage consumption of calories. Mr. [redacted] was seen multiple times by the dietician and medical director for his ongoing weight loss, lab studies were obtained, and he was offered preferred foods and supplements. In addition, he was provided with opportunities to eat in private so that the issue of control was eliminated.

- Given his developmental delay, multiple impairments and complex presentation, it was difficult to differentiate behavioral from mood-related symptoms. Mr. [redacted] was seen by members of Lakeview's psychiatry/psychology/behavioral health services team 9 documented times in addition to the frequent contact with his Cabin/Program Manager (a behavior specialist) during his 72 day stay. Further, given the behavioral challenges presented, he was not an appropriate candidate for individual counseling or "talk" therapy to address these symptoms. The most probable route for improvement was through behavioral treatment approaches which were implemented and modified during his stay.

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    - Mr. [redacted]'s pre-admission records regarding probable efficacy of various modes of treatment confirm these treatment strategies which were

approved at his team meetings. Referencing a New Hampshire Hospital Psychiatrist Progress Note from [redacted], Christine Morris, ARNP (at the time Mr. [redacted]'s prescriber) noted, "Did feel his symptoms were due to his intellectual disability and not a major mood disorder or a psychotic disorder. New plan (somewhat restrictive) recently put in place in that Mr. [redacted] is held accountable for his actions, asked to take care of his ADLs, participate in treatment, etc. These likely to be contributing to his increasing anger and intermittent hostility." Mr. [redacted]'s behavior was being managed in accord with a Lakeview behavior plan written by a doctoral level, Board Certified Behavior Analyst based on a functional assessment of his behavior which was consistent with the "effective" behavior plan he arrived with.

As a result, neither [redacted]s guardian nor other members of his treatment team not employed by Lakeview were aware of [redacted]'s ongoing refusal to take medications, including his anti-seizure medication, or his near complete refusal to eat during the month preceding his death (p. 1, 2nd paragraph 8th sentence).

- Lakeview acknowledges that early management of this case was of concern and, as a result, communication with external stakeholders suffered. Mr. [redacted] did refuse medications on several occasions during the month of September. However, he only refused his seizure medications on one occasion (9/21/12) during the month of September. Further, lab results at the time of Mr. [redacted]s death indicated that his seizure medication remained in a therapeutic range.

DRC requested, but was denied access to, Lakeview's internal death investigation report (p. 2, Section I, 2nd sentence).

- Lakeview exercised its statutory obligation to protect the confidentiality of quality assurance documentation in a case that could result in litigation.

Although the DRC interviewed nearly every staff member who had contact with [redacted] during the weekend he died, Rachel Emond, the LPN who administered CPR to Mr. [redacted] the morning of his death, declined DRC's request for an interview (p. 3, paragraph 1, 7th sentence).

- It is not clear what this assertion on the part of DRC is intended to imply. Ms. Emond's initial refusal to be interviewed was a trauma response. She participated in supportive counseling, provided by Lakeview, and was finally able to participate in an interview conducted by BDS/OCLS investigators. There was an agreement with BDS/OCLS investigators for transcripts from that interview to be shared with DRC representatives.

Discussion about weight loss (p. 7 + 8)

- According to available records, weights taken at New Hampshire Hospital and upon admission to Lakeview indicate that Mr. [redacted] was losing weight at New Hampshire Hospital (~ 7 pounds) and continued to lose weight (~ 40 pounds) at Lakeview at roughly 3.5 and 4.1 pounds per week respectively. Based on [redacted], Mr. [redacted] may have had a slight weight gain in the 5 day period prior to his death.

To the contrary, despite the challenges [redacted] presented regarding program participation, medication and meal refusals, on [redacted], Lakeview mailed a letter and information to his guardian indicating that [redacted] tolerated his evaluations well and "is adjusting well to his residential setting."

- The information contained in the letter was from the initial Service Plan meeting, which occurred on [redacted] It reflected general information from his first 10 days of admission, at which time none of Mr. [redacted]'s behavior drastically varied from the behaviors he was exhibiting prior to admission to New Hampshire Hospital or while at New Hampshire Hospital. Mr. [redacted] also was not exhibiting any of the extreme behaviors noted in his preadmission paperwork, such as self-injury, elopement, or aggression.

Lakeview did not inform [redacted]s guardian of the seizure resulting in his [redacted] hospitalization until [redacted] – two weeks after he was hospitalized – during a scheduled team meeting...No indication of notification after 2nd seizure on [redacted] (Paraphrased) (p.10, paragraph 3).

- Lakeview acknowledges that case manager communication was not consistent with our expectations. However, in both instances, Mr. [redacted] was transported immediately to Huggins Hospital, with whom Lakeview has a longstanding history demonstrating routine fulfillment of their legal responsibility for notification of the guardian with whom they are required to communicate regarding treatment. In this instance, it was not unreasonable for Lakeview to expect that Huggins Hospital personnel contacted the guardian per protocol, as the legal responsibility rested with the treating hospital for obtaining guardian consent prior to administering treatment. While Huggins Hospital records cannot be obtained for verification by Lakeview, their staff confirmed that this has always been and continues to be their policy for all patients, including those sent by Lakeview.

According to Dr. Cooley, DRC's consulting physician, the presence of large ketones in Mr. [redacted]'s urine indicated that he was in a metabolic state of starvation (p. 15, last sentence of 1st paragraph).

- It is important to note that the presence of ketones is representative of fasting not "starvation", as even an overnight fast can affect this level. Mr. [redacted] s ketones were slightly elevated when Dr. Badman evaluated him on [redacted]. This effect could be further exacerbated by Zonisamide, a drug which Mr. [redacted] was taking regularly for seizure management. Zonisamide is well known to cause metabolic acidosis which can produce ketones in the urine. Dr. Badman was therefore not unduly alarmed by the elevated ketones which never measured in an extreme range warranting an acute intervention.

Contributing Information not included in the report

Dr. Badman received a copy of the Medical Examiner's report as filed by Dr. Andrew. Upon Dr. Badman's review of this document, several questions arose related to statements in the Medical Examiner's report which do not appear to be supported by the objective findings.

- Dr. Badman referenced that the blood work he ordered and had been drawn less than 48 hours before death on [redacted], showed no indication of dehydration with normal BUN and creatinine levels, and a normal sodium level of 133. Additionally, Mr. [redacted] was observed by Dr. Badman to drink down a full cup of water at his check-up on [redacted] and at that check-up, demonstrated no objective signs of dehydration. Mr. [redacted] reportedly both went to the bathroom and was found lying in urine the morning of [redacted], which is inconsistent with dehydration. [redacted]

- Dr. Andrew agreed [redacted] Dr. Andrew additionally commented [redacted]

- Dr. Badman reports that Zonisamide is well known to cause metabolic acidosis which can produce ketones in the urine, and thus [redacted]

[redacted] Dr. Andrew further indicated that the only reason the acetone level was requested was because he had been 'told' of decreased intake and dehydration, and not because of any specific findings indicating decreased intake or dehydration at autopsy.

Summary

Mr. [redacted]'s life came to an abrupt and unexpected end. The cause of death was found to be chronic seizure disorder, and deaths of this nature are unfortunately common as noted in the relevant literature. [redacted] The manner in which staff managed Mr. [redacted]'s care during the last hours of his life was not consistent with Lakeview's mission or expectations, and plans of correction have been implemented through our quality assurance program to address identified concerns. Throughout his stay at Lakeview, Mr. [redacted]'s clinical team was working to help him make positive behavior changes, regulate his eating, and manage his seizures as evidenced by his relative behavioral stability and weight stabilization/gain in his last 5 days of life and 40+ contacts documented in his 72 days. Lakeview was prepared to continue to try new methods of motivating Mr. [redacted] to participate in programming. The reality is that Mr. [redacted] had extremely challenging behaviors that could not be managed in other settings, which required placement at Lakeview. He received extensive therapeutic assessment and follow-up related to the reasons for his referral. Review of Mr. [redacted]'s case reflects several quality assurance focus areas that Lakeview has taken very seriously. However, as a whole, the record reflects treatment failure (given the pre-existing nature of these conditions) versus neglect.

We remain dedicated to continuous quality improvement to ensure mitigation of any contributory factors under our control. Given the significant amount of information contained in this letter and the alternative conceptualization of the facts, we welcome an opportunity to address any questions that may arise.

Thank you for your dedication to the persons we serve. Please contact me know if you have any questions.

Sincerely,

/s/ Edwinna C. Vanderzanden

Edwinna C. Vanderzanden
For Lakeview NeuroRehabilitation Center, Inc.

ECV/ljl [redacted]