Report of an Investigation into the Circumstances Leading to the Death of J.D., a Resident of Lakeview Neurorehabilitation Center

Executive Summary

On [redacted] 2012, "J.D."[1], a twenty-two (22) year old young man with a known history of depression and developmental disabilities as well as a seizure disorder, died in his residence at Lakeview Neurorehabilitation Center in Effingham, New Hampshire ("Lakeview"). He had been at Lakeview for only seventy-two (72) days at the time of his death.[2]

Shortly after J.D.'s death, the Disability Rights Center - NH ("DRC"), New Hampshire's designated protection and advocacy system, received reports alleging that Lakeview's actions or inactions with respect to J.D.'s treatment and supervision may have caused, or led to, J.D.'s premature death. In particular, DRC received reports alleging that during his brief time at Lakeview, J.D.'s physical and mental health sharply declined and that Lakeview failed to provide appropriate medical care and behavioral interventions to address J.D.'s healthcare needs. Further, DRC received reports alleging that Lakeview failed to inform J.D.'s legal guardian, family members, the Area Agency that funded his placement or community residential services providers of the extent of J.D.'s declining physical and behavioral health; thereby depriving these individuals of the information necessary to consider options to address these concerns, including possibly terminating his placement at Lakeview and moving him to a different setting.

[1] "J.D." is a pseudonym assigned to protect this individual's privacy. In addition to using a pseudonym, DRC has redacted information, such as dates, which could lead to J.D.'s identity. In some instances in which confidential information has been removed, DRC has added clarifying information, in brackets, to provide contextual information for the reader. An un-redacted version of this report, including J.D.'s identity, has been provided to individuals and officials who have the authority to obtain this information, e.g. Lakeview Neurorehabilitation Center, the NH Department of Health and Human Services.

[2] Prior to his admission to Lakeview, J.D. had lived successfully with a caregiver in his home community for approximately 2 years. Unfortunately, J.D. was required to move to a new provider in a different community. He did not adjust well to his new surroundings. J.D.'s residential provider raised concerns about his safety which resulted in his involuntary admission to New Hampshire Hospital and then his placement at Lakeview for a short term basis until an appropriate community-based residential placement could be arranged.

Pursuant to its federal authority, DRC conducted an investigation of the circumstances surrounding J.D.'s death to determine whether Lakeview's actions or inactions constituted abuse or neglect and/or contributed to, or caused, his death. DRC's investigation focused on the care and treatment J.D. received at Lakeview including medical, mental health, crisis intervention services, general supervision and residential care. DRC reviewed Lakeview's efforts to communicate pertinent information regarding J.D.'s health status with, and seek input from, J.D.'s legal guardian and other individuals involved with his treatment in his home community. DRC reviewed J.D.'s records maintained by Lakeview as well as relevant policies and procedures in effect at Lakeview. DRC interviewed Lakeview residents who had lived with J.D., staff members who worked with J.D., his legal guardian and other individuals involved with his care and treatment. In addition, DRC reviewed reports regarding J.D.'s autopsy which were completed by the New Hampshire Office of the Chief Medical Examiner.[3] DRC reviewed a report concerning J.D.'s treatment while at Lakeview authored by Dr. Carl Cooley, Chief Medical Director at Crotched Mountain Foundation, an expert retained by DRC to assist with this investigation. DRC provided a draft investigation report to Lakeview for its review and response prior to issuing this report. DRC reviewed Lakeview's response, which was provided by its attorney, obtained additional consultation from Dr. Carl Cooley regarding Lakeview's response and reviewed a supplemental report authored by Dr. Cooley pertaining to Lakeview's response to the draft investigation report.

After carefully reviewing the above-referenced information, the DRC concluded that Lakeview's actions and inactions including, but not limited to, the conduct of various administrators, consultants, and staff members with regard to J.D.'s treatment constituted neglect

[3] Due to Confidentiality Requirements, the Chief Medical Examiner's Report is not included with this Report. In addition, in accordance with the Chief Medical Examiner's instructions, information contained in the Chief Medical Examiner's Reports, other than cause and manner of death, have been redacted.

as defined by relevant New Hampshire and Federal laws. Further, DRC determined that the deficiencies DRC uncovered likely led to J.D.'s untimely death.

DRC's most significant findings include the conclusion that Lakeview inadequately responded to clear warning signs of a serious health condition, in particular: J.D.'s refusal to eat and loss of nearly 50 pounds in only ten (10) weeks, a refusal to take prescribed medications as directed by a physician and his guardian, two hospitalizations for prolonged seizures, expressed suicidal ideation, and a lack of participation and engagement in nearly all activities. Further, Lakeview failed to adequately track, and assess the impact of, J.D.'s weight loss, ensure staff complied with J.D.'s supervision requirements, and failed to secure medically-indicated lab work in a timely manner. While under Lakeview's supervision and care, J.D.'s overall health declined to the point where he was in a metabolic state of starvation and his medication levels had likely dropped well below therapeutic levels. Despite this, in his final days and hours, J.D.'s physical and mental health status did not appear to be of much concern to many of Lakeview's staff members, including medical and clinical staff.

The morning he died, direct support staff noted that J.D. was naked and lying on the floor in a pool of urine. An overnight staff member who reportedly observed J.D.'s condition at approximately 5:00 a.m. suspected he had experienced a seizure. Yet, instead of contacting health services, or attending to J.D.'s physical condition, this staff member, and subsequent staff on duty, left him and attended to other residents. Several hours after staff first noted J.D.'s condition, another direct support staff member noted J.D. was "nonresponsive." Rather than assess whether J.D. was conscious or call for assistance, he simply left J.D. alone and tended to other residents. It was not until more than four hours after J.D. was observed lying on the floor that one of Lakeview's nurses, who had come to deliver medications, noticed that J.D. was not

breathing, called for help and began administering C.P.R. J.D. was likely deceased at that point, but was not pronounced dead until his arrival at Huggins Hospital, at approximately 10:30 a.m.

Additional findings include failure to provide timely evaluations or develop an individual service plan, and failure to conduct a functional behavior assessment or modify J.D.'s behavior plan to address continuing resistance to food and medication intake. Further, Lakeview failed to ensure sufficient staffing levels to provide J.D. with the level of supervision ordered by Lakeview's psychologist. Lakeview failed to provide timely, and full, information regarding J.D.'s declining health status to J.D.'s guardian, the Area Agency that served him or community-based residential care providers who had expressed concern for his well-being. Finally, DRC found that Lakeview's system of care lacks the necessary level of interdisciplinary communication and coordination to meet the treatment needs of residents with complex emotional, behavioral and medical needs, such as J.D.

Individuals with disabilities, including those with long-term care needs, are legally entitled to receive services in the most integrated setting appropriate to their needs.[4] The "most integrated setting" is one that enables individuals with disabilities to interact with nondisabled peers to the fullest extent possible. [5] This is generally accomplished through serving individuals in their home communities with necessary supports and services.[6] Unfortunately, while J.D.'s placement at Lakeview may have been precipitated by behavioral challenges he presented in the community, it appears that the decision to move J.D. from his community residence to New Hampshire Hospital and finally to Lakeview was driven less by J.D.'s needs than by the lack of alternative appropriate community-based options. The circumstances surrounding J.D.'s death

[4] Olmstead v. L.C., 527 U.S. 581 (1999)
[5] 28 C.F.R. pt. 35 app. A (2010)
[6] *See* e.g. R.S.A. 171-A:1. ("The policy of this state is that persons with developmental disabilities and their families be provided services that emphasize community living.")

serve to reinforce the critical importance for New Hampshire to develop the community-based capacity to meet the needs of individuals, such as J.D., who, from time to time, require enhanced services to live safely in their home communities.

In the interim, and to the extent that individuals continue to receive residential services at Lakeview, DRC offers recommendations to improve the safety, treatment and well-being of Lakeview's residents and to prevent the type of tragic outcome J.D. suffered in the future. A summary of DRC's recommendations follows.

1. Lakeview should ensure there is appropriate coordination among the three domains of medical care provided at its facility (i.e. medical, neurologic, and psychological/psychiatric) as well as a good communication between direct care staff and clinical professionals. Further, Lakeview should ensure that any time one of its medical or clinical professionals examines or evaluates a resident's healthcare needs, that the examining/evaluating healthcare professional receives sufficient information from the individual, his or her guardian, direct support staff and other medical/clinical professionals to secure a full picture of the resident's health status to complete a History of Present Illness. Finally, Lakeview's medical and clinical providers should take all steps necessary to ensure their treatment recommendations are provided in a timely manner to residents and adhered to by all staff members charged with implementing these recommendations.

2. When presented with a situation, such as J.D.'s, in which a resident's behaviors and health status are rapidly deteriorating, Lakeview should immediately convene a multi-disciplinary team meeting to consider amendments to the individual's treatment plan or, if medically indicated, to determine whether the resident requires a higher level of care than is available at Lakeview.

3. Lakeview should amend its Family Notification Policy to require that its case manager have weekly contact with residents' legally-responsible parent(s) or guardian(s) and provide timely information regarding accidents, injuries, illnesses, or "unusual incidents" in accordance with this policy. Lakeview's policies should be amended to specifically define and/or enumerate a non-exhaustive list of the types of incidents **c**onsidered to be "unusual" and, therefore, must be reported to the parent/legal guardian. In addition to notifying the parent/legal guardian of accidents, injuries, illnesses and incidents with police or public involvement, this policy should require timely communication with the parent/legal guardian to inform them about medication, food and/or program participation refusals, changes in medications, changes in supervision levels, and any recommended changes in treatment or behavior plans.

4. Lakeview should take all steps necessary to ensure that case management staff members timely obtain relevant information regarding the clients for whom they are responsible. Further, Lakeview should take all steps necessary to ensure that case management staff members provide relevant information to residents' parents and legal guardians on a timely basis.

5. Lakeview should timely convene a meeting of responsible parties, including the guardian and funders (e.g. area agency) to identify alternative providers, plan for, and effectuate, the individual's transfer to an alternative setting when, as in J.D.'s circumstances, an individual's health and safety are threatened by his or her deteriorating condition and Lakeview is unable, for any reason, to timely correct or ameliorate the condition.

6. Lakeview should immediately address and resolve communication deficiencies between and among professional and direct care staff to ensure that all staff members who have contact with residents are aware of, and comply with, each resident's current level of supervision.

7. Lakeview must maintain sufficient staffing levels in each of its residences to meet the supervision needs of each of Lakeview's residents, i.e. there should be sufficient staff available to meet the supervision levels ordered by Lakeview's clinical staff and/or residents' treatment teams at all times. No staff member should ever be left alone in living quarters with more than one resident.

8. Lakeview should amend its emergency response protocol to clearly define what constitutes a "medical emergency," by including examples such as: seizures, allergic reactions, choking, serious injuries, loss of consciousness, respiratory arrest and cardiac arrest. Further, Lakeview should train, and test to verify understanding, each and every direct care staff member on its emergency response protocols including, but not limited to, the steps staff should take in the event that a resident has experienced a medical emergency including whenever a resident appears "unresponsive." Finally, Lakeview should provide its direct care staff with periodic training to reinforce and refresh their understanding of Lakeview's emergency response protocols.