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Governor Nikki Haley
1205 Pendleton Street
Columbia, South Carolina 29201

James H. "Jay" Lucas
Speaker, South Carolina House of Representatives
506 Blatt Building
Columbia, South Carolina 29201

Alan Wilson
South Carolina Attorney General
1000 Assembly Street
Columbia, South Carolina 20201

Lieutenant Governor Henry D. McMaster
PO Box 142
Columbia, South Carolina 29202

Dear Governor Haley, Attorney General Wilson, Speaker Lucas and Lt. Governor McMaster:

March is Brain Injury Awareness Month. I am writing in hopes that the State of South Carolina will take immediate action to prevent the institutionalization of Rob Levin, who receives services under the Head and Spinal Cord Injury (HASCI) program operated by the South Carolina Department of Disabilities and Special Needs, under contract with the South Carolina Department of Health and Human Services. I am enclosing the affidavit of Mr. Levin's treating physician, which clearly describes the services required to prevent Mr. Levin from being institutionalized. Mr. Levin was injured at Ground Zero in the days following 9/11 and he spent four years in a nursing home in North Augusta prior to returning to live at home ten years ago.

DHHS has taken the position that Mr. Levin is not at risk of institutionalization, thus requiring his sixty-six year old mother, Mrs. Self, to provide tube feedings and other care for her son 105 hours a week. We have appealed the federal court's decision (that Mr. Levin is not at risk of institutionalization) to the Fourth Circuit Court of Appeals. Recently, Mr. Levin's step-father, a disabled Viet Nam veteran, suffered a stroke and has been diagnosed with brain tumors. Now, Mrs. Self is being stretched to the breaking point, between providing care for her husband of thirty-eight years and her son. She has sought to admit her son to a nursing home until the needed home-based services are provided and he has been placed on waiting lists. There is certainly no doubt that Mr. Levin is at risk of institutionalization, as a request to place him in a nursing home is being processed as I write this letter.

We have requested additional nursing and personal care services from DHHS and DDSN to avoid institutionalization, but the agencies' only response has been to offer to admit Mr. Levin to a DDSN Regional Center ICF/ID. The enclosed affidavit of Rob's treating physician explains why this placement in an intermediate care facility for persons who have intellectual disabilities would be an inappropriate and dangerous placement for Mr. Levin, who DHHS has each year

found to require skilled level of care. In addition, I call your attention to the recent \$1 million settlement in the case of Fantasia Jackson at the Pee Dee Center and the long history of abuse and neglect in DDSN Regional Centers.

The obligation to provide services in the least restrictive setting, i.e. Mr. Levin's home, is that of the State of South Carolina, pursuant to the Americans with Disabilities Act and the decision of the United States Supreme Court in *Olmstead v. L.C.* Of course, if the State chooses to provide these service through the HASCI Medicaid waiver program, the federal government will pay approximately 70% of the costs. But, as Judge Hendricks recognized in *Peter B. v. Sanford*, the State's obligation to comply with the Americans with Disabilities Act exists separate and apart from that funding source.

We now know Mr. Levin's services were reduced based on blatantly false claims of "budget reductions," and that DHHS allowed \$225 million in state funds to "lapse" that year. According to a GAO audit, despite drastically reducing services to persons like Rob, that year DDSN overbilled Medicaid by more than \$10 million. In a subsequent year, DHHS failed to spend more than \$280 million it received from the General Assembly. **The State of South Carolina has replenished its reserve accounts on the backs of severely disabled persons like Rob.** Governor Haley included more than \$13 million in DDSN's budget in FY 2014 to provide new services, which should have been matched with federal funds to produce more than \$40 million in services and jobs for South Carolinians to serve people like Rob. However, DDSN only spent approximately \$4 million of these funds as allocated by the General Assembly. This is not an issue of lack of funding. The diversion of funds intended to provide services for people like Rob, who have severe disabilities, has been recurring and ignored by the Governor's Office and the General Assembly.

We are sending this letter to each of you as a courtesy in an attempt to avoid litigation in the state court. We plan to file a complaint naming the Governor and members of the General Assembly for the State's continuing violations of the Americans with Disabilities Act and the Medicaid Act. You may reach me at 803 360 5555 if you would like to work together to immediately resolve this family's crisis.

Cordially,



Patricia Logan Harrison

cc: Damon Wlodarczyk, Esq.
Senator Chuck Grassley, attn. Karen Summer
Senator John Scott
Senator Joel Lourie
Senator Lindsey Graham
Senator Tim Scott
Representative Joe Wilson
Clare Ansberry, *Wall Street Journal*
Seanna Adcox, *The Associated Press*
Liv Osby, *Greenville News*
Sumter Item

John Monk, *The State*
Ron Aiken, *The Nerve*
Eric Bradner, CNN
Joseph Weber, Fox News
Robert Pear, *The New York Times*
Gloria Prevost, P&A
David Wright, CMS Atlanta
Ed O'Keefe, *Washington Post*
Yvonne Wenger, *Baltimore Sun*
Lauren Sausser, *Charleston Courier*

AFFIDAVIT OF CHARLES G. SHISSIAS, M.D.

1. I am a licensed physician and have practiced medicine since graduating from the Medical University of South Carolina in 1994.
2. I am board certified in neurology and board eligible in psychiatry, having completed combined neurological and psychiatry residency training, in addition to a movement disorder fellowship.
3. Rob Levin is a forty-four year old man with severe and life-threatening disabilities, including: brain injury, spastic quadriplegia, heart and lung disease, a seizure disorder, and a history of aspiration pneumonia and urinary tract infections.
4. I have been Robert Levin's neurologist for ten years and have seen him for regular visits at least four times a year since I was a partner at the South Carolina Neurological Clinic in Columbia.
5. When I relocated to the Low Country Medical Group in Beaufort, I continued to treat Rob, because he was turned away by my old clinic after I left.
6. Rob has quadriplegia, chronic pain, seizures and heart and lung diseases and he requires total care in all activities of daily living, but he is totally nonverbal and he cannot describe what he needs or where he hurts.
7. Rob has been treated for depression and anxiety since his head injury and he communicates pain or agitation by making a high pitched cry or grinding his teeth.
8. Rob also communicates pain by swinging his right arm, but he does not have purposeful use or movement of even that arm.
9. In 2014, I ordered 60 hours of nursing services, based on my first-hand knowledge of Rob's medical condition and objective medical evidence, including, but not limited to clinical and laboratory findings over the course of years of providing medical care to Rob, the large number of medications he requires each day, the number of times throughout the day and night when he must be administered nutrition and medications through a gastric tube, and the need for continuous and comprehensive nursing assessments of his physical and mental condition.
10. As I testified in the district court, my 2014 order of 60 hours a week of nursing services was a bare minimum that was based on the care then being provided by his mother, who is an RN and was available and willing to provide nursing care during other hours of the day.
11. In addition to nursing hours, I ordered personal care attendant services at all times when a nurse is not present.


12. Rob is totally incontinent of bowel and bladder, he requires breathing treatments and suctioning regularly during the day and night, most frequently when he is congested.
13. My order for nursing and personal care hours was based not only on Rob's medical condition, but also on my knowledge of the fragility of Rob's support system at home.
14. I can state unequivocally that the care and support that Rob has received at home from his mother has been exceptional and that is why he has remained relatively strong and healthy, given the severity of his permanent disabilities, but that delicate support system does not negate the very real and over-looming risk of institutionalization.
15. His mother, who is a registered nurse, has provided excellent nursing care, providing opportunities for Rob to have interactions with non-disabled persons, stability, stimulation, and attention that he could never receive in a state facility or private nursing home.
16. My staff and I have worked with Rob's mother for ten years, personally witnessing her age over time and seeing her own physical strength decline, despite her heroic attempts to put up a good front and not complain.
17. Based on my interactions with Rob and his mother, I believe that she has needed significantly more help for a long time, but it has been difficult for her to admit that she can not physically continue to provide the care she has been providing Rob in her home since his discharge from the nursing home.
18. Based on this first-hand knowledge, as well as my experience treating other head injury survivors who are cared for at home, I know how taxing the job is on the family, and that it is not reasonable to expect a sixty-six year old mother to maintain the pace she kept when she was fifty-six years old.
19. My experience has been that once a carefully established system for keeping a seriously disabled patient at home is dismantled, even by a short admission to a nursing facility, it is often impossible to reassemble the team that has gone on to accept other assignments, resulting in what was intended to be a temporary admission becoming a permanent placement.
20. If Rob's mother suffered even a minor injury that required hospitalization or loss of strength, there would be no alternative but to institutionalize Rob, which is why it is so important to provide the supports his mother needs to keep her healthy and Rob at home.
21. I have been informed that Rob's step-father has recently suffered a stroke and has a brain tumor, requiring his mother to spend most of her time providing care and support to him and requiring Rob's mother to now perform all of the household chores that for years had been performed by his step-father.

22. Based on these changed circumstances, it is my medical opinion that Rob now needs to have 84 hours a week of nursing services, in addition to personal care attendant services at all hours when a nurse is not present.
23. If these hours are not provided, there is not just a *risk* of institutionalization, but an unpreventable *certainty* that he will be institutionalized.
24. Rob clearly meets the requirements for skilled level of care and his health and safety cannot be protected in a DDSN Regional Center that provides intermediate level of care.
25. When a person meets skilled level of care, that means that the patient must have licensed nursing staff available in the facility 24 hours a day to provide direct care and to make decisions regarding the patient's care.
26. Most nursing home residents do not need skilled care, instead they need an intermediate level of care, which involves custodial care, i.e. helping the resident with activities of daily living (bathing, eating, dressing, toileting, transferring from bed to wheelchair or wheelchair to bed and moving around).
27. It would be medically inappropriate and extremely unsafe for Rob to be admitted to any facility that provided him with intermediate level of care or anything less than skilled nursing care.
28. Placing Rob in an ICF/ID (formerly ICF/MR), which is an institution that provides care for patients with intellectual disabilities (formerly "mental retardation"), would cause him to digress mentally and emotionally and would place him at risk of premature death.
29. Rob's immune system is depressed and institutionalization will likely lead to sepsis from bodily wounds and aspiration pneumonia.
30. It would be dangerous for Rob to be left alone in an institutional setting, especially a facility with cognitively impaired, aggressive patients, and, any patient who wandered near Rob would be at serious risk of physical injury himself, if he came within the reach of Rob's right arm, so Rob would have to be segregated from other patients.
31. At home, there is no risk of Rob being injured by an aggressive patient, but that risk would increase exponentially if he were placed in a DDSN institution where he would be unable to defend himself, because he does not have the capacity to control his movements or to get away.
32. The changes in staffing that occurs in nursing homes would be problematical, and would not only result in Rob not receiving the care he needs, but caregivers who are not intimately familiar with his behaviors and triggers would be placed at risk of harm themselves.

33. It would be imperative that Rob receive one-on-one supervision in a nursing facility and he would need to have the continuity of caregivers who are familiar with him, his triggers, and with his treatment regimen, because the part of his brain that controls impulses is damaged.
34. Rob is a large man who, surprisingly, has considerable upper body strength (but not control), so, if Rob did not have one-on-one supervision in a nursing facility, I am certain that he would have to be restrained, either chemically, or with physical restraints, thereby leading to an increase in his anxiety and depression.
35. As I testified in the district court, in a nursing facility, Rob would be at significant risk of a caregiver making a wrong decision regarding restraints and causing him irreparable harm.
36. I have not changed my opinion that Rob would be at serious risk of premature death if he were to be placed in a nursing facility.
37. Rob's quality of life and opportunities to interact with non-disabled persons would be practically non-existent in an institutional setting.
38. Not only would Rob be at greater risk of developing decubitus ulcers and institution-acquired infections, but Rob has seizures which can be triggered by stressful and unfamiliar situations.
39. Rob has a carefully established schedule for feeding and administration of medicines by gastric tube during the day and he receives nutrition throughout the evening that must be monitored to prevent aspiration.
40. The area where Rob's gastric tube is inserted into his abdomen must be kept thoroughly clean and covered, but if Rob were left alone in an unfamiliar setting, it is likely that, out of frustration, he would pull out his gastric tube, resulting in leakage around the insertion site and requiring surgery to replace the tube.
41. Tension on the tube could also result in pressure necrosis (death of an area of tissue) of the interior abdominal wall, leading to gastric hemorrhage, peristomal leakage, infection, stomal leaks, tube extrusion or migration, aspiration and fistula formation.
42. The stoma site must be observed by a nurse for redness, swelling, necrosis or purulent drainage, and Rob's skin must also be cleaned daily, observing infection control procedures.
43. It is remarkable that Rob has not developed decubiti and serious infections at home, but that risk will be astronomically increased if he is institutionalized.

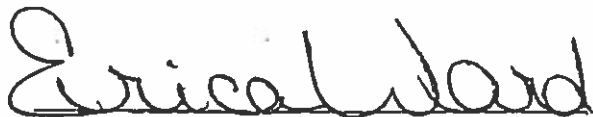
44. Rob could benefit from physical therapy, but it is my understanding that those services are no longer offered through the DDSN Medicaid waiver.

I have read this statement and swear, under penalties of perjury, that it is true and correct, to the best of my knowledge and belief.


Charles G. Shissias, M.D.

Sworn to before me on this 4th day
of March, 2016.

ERICA WARD
Notary Public
South Carolina
My Commission Expires 05-25-2017



Notary Public for South Carolina