

Olaf A. Soot
9 Tomahawk Lane
Greenwich, CT 06830
(203) 661-5491
hotwheels860@yahoo.com

February 23, 2009

To Chairman Walker, Chairman Doyle, and members of the Human Services Committee:

H.B. No. 6443 (Raised) An act concerning direct billing for home care nursing services provided to Medicaid recipients.

Thank you for giving me the opportunity to testify on behalf of Raised Bill H.B. 6443. My name is Olaf A. Soot, a longtime resident of Greenwich, Connecticut. I am a 48 year old man afflicted with Duchenne Muscular Dystrophy (DMD), a muscle destroying disease with no cure. I can not move any of my extremities and require the use of a ventilator 24 hours a day to stay alive. This circumstance is made all the worse with aging parents and the severe nursing shortage.

I receive skilled nursing care at home through Connecticut's Title 19 Medicaid program. I am grateful for this program, because it has allowed me to stay at home with my parents and have a decent life in spite of my terminal disease. Home is most definitely where the heart is. I can not imagine a life separated from my loving family and friends. The closest nursing home that accepts ventilator patients is at least an hour's drive from my home. I doubt that I would be alive today if I had to live in a nursing home.

The state of Connecticut requires Title 19 recipients to use state Medicaid approved home healthcare agencies to receive nursing services in the home. Unfortunately, there are some major problems inherent with the way this program delivers services. On average an agency takes in for themselves at least \$8-\$10 dollars of state Medicaid funds for every hour a nurse works. I am approved for twenty four hours of skilled nursing care. That means that my agency can make on average \$240 a day on just my case and \$1680 in one

week. These funds could be used to attract qualified nurses to home care.

I do not want to eliminate agencies all together. Medicaid recipients should have the choice whether or not to use agencies. Just last week I phoned about 50 agencies statewide. Only a couple of them would even consider my case. Most do not have enough qualified nurses to work on a ventilator case.

My current agency and previous one have been unable to find a qualified nurse for me in over two years. We have mainly one highly qualified and experienced LPN, who works long hours. My 76 year old mother and 79 year old father help me at night. When my parents are away, we still have to rely almost exclusively on that one excellent nurse. As good as she is, she needs more help. For most of my other nurses they can only work a few hours because this is there second or third job. Their primary job pays them more money and offers more complete benefits.

Homecare agencies pay less money and provide little or no benefits.

The agency system is not doing what it was intended to. Most home healthcare agencies do not want to take on Title 19 ventilator cases like mine. The agencies complain that the state reimbursement is slow and insufficient. In addition, the agencies feel the states' paperwork is onerous and overly complicated. The agencies realize they can not attract enough qualified nurses at the rates they offer. Many nurses do not feel any incentive to sign up with the agency because of the subpar hourly rates.

Last year, while recuperating from pneumonia and a near-death experience in the hospital, my nursing agency told me they would send me to another agency. The owner of the agency explained to me that it was not profitable to continue having me as a client. He said and I quote, "You're a smart guy. This is business."

Many patients' families including mine are forced to supplement nurse's agency rates or go without nurses. All in all, it is a very scary situation for me and others like me.

How can you our legislators help improve the well being of your constituents who like me require skilled nurses in the home to live? If you allow RNs and LPNs to directly bill Medicaid their compensation will be greater and they will more likely choose employment in home care.

If we allow unskilled health care workers in the form of Patient Care Assistants to directly bill Medicaid, I ask you why would you deny a licensed registered nurse or licensed practical nurse to obtain a Medicaid provider number and bill the state directly?

The prospect of not having qualified nurses is truly frightening for me. I do not want to end up in a nursing home. I implore the legislature to pass H.B. No. 6443. Passage would make home care more competitive, because the nurses would receive more money per hour. Passage would also insure access to Medicaid funds for recipients.

In a time when we are all aware of the dire nursing shortage, I ask you to help me remain in my home by making it easier for me to find qualified licensed nurses.

This country just elected a President who spoke of change. Let us change the system for the better. The ultimate answer is for people not to get sick, but that is impossible. Illness does not take a holiday. Please do not tell me that passage of this bill will take time because time is what I do not have.

Sincerely yours,

Olaf A. Soot.