

Please submit for the record for the
Human Services Committee
Hearing of March 11, 2010



Sara Hadden
10 Talcott Mountain Road
Simsbury, CT 06070

February 18, 2010

Senator Toni Harp and Representative John Geragosian
Legislative Office Building
Hartford, CT 06106-1591

Re: DDS attendance-based reimbursement unworkable

Dear Members of the Appropriations Committee:

My name is Sara Hadden. My husband David and I are the proud parents of the young man Jamie, pictured above. He is 29 years old, developmentally disabled, non-ambulatory, blind and in need of assistance with all aspects of daily living. He currently lives in a group home managed by Oak Hill, and attends a Day program at Harc, Inc. five days a week, from 9:30 to 2:30 each day.

We are deeply concerned for the viability of the essential programs and services these two agencies provide for our son and hundreds of others with similar needs throughout the state. Budgetary cuts and the absence of a COLA in recent years have stressed their resources to the breaking point. Now, DDS has implemented a fee for service program that requires each consumer of day services maintain a 90% attendance record to qualify for reimbursement. Given the fragility of health and behavioral issues in this population, a 90% attendance requirement is insensitive at best, and at it's worst, singles out those individuals most in need of compassionate treatment, and turns a cold shoulder to them.

Last week I reviewed Jamie's doctors' appointments for the upcoming year to make sure his medical appointments would not impact his attendance record at Harc day program. There are currently six medical appointments scheduled in March. Of these, only one had to be rescheduled, as we strive to get him to day program as much as he can. When I talked with the doctor's office, no other

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appointments were available until April. The purpose of the visit is for a Botox injection in Jamie's fore arms and chest muscles to relieve painful spasticity and prevent the development of wrist and shoulder contractures. These injections greatly improve his comfort, and the ease with which his care givers can bathe and dress him. A months delay would hurt Jamie.

Another appointment, later in March, is for Jamie's annual physical. He is due for a bone scan there to determine if his bones have become more brittle in the past year. To do the scan and the physical exam in the same day requires too much time. The choice becomes whether to make two separate appointments on two separate days, so Jamie can get to day program on time to have it count as a day of attendance. (To do it this way would require additional staff time at his group home.) Later in the year we have another appointment that will require a full day off for a colonoscopy and endoscopy. These are absences we know to count against his future attendance. Then there are the unforeseen absences. Last August Jamie was scheduled for an outpatient procedure that was to require a two or three day absence. He developed an infection that required almost four weeks in the hospital and one more at home recovering before he returned to his day program.

While Jamie was absent, his aide at Harc was reassigned to cover other staff member's vacation-days and callouts. She was not idly waiting for Jamie to return. The resources in these programs are calculated to be used efficiently and yet, it is essential the infrastructure be maintained for when these individuals are well enough to return.

When Jamie is at Harc he is a happy and engaged young man. He is like Norm in the old television sit-com 'Cheers'. Everybody knows his name.

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He loves the van ride there, with his house-mate Akeem. The radio is on and his wheelchair gently bounces in the van, he's cruising. He recognizes the quick blast of cold air in the parking lot, the calls of 'hello Jamie' in the noisy lobby, the quieter ride up in the elevator and Migdalia's unmistakable warm greeting--a touch and voice he has known, and has given him his bearings, for seven years. Recently, I was visiting Jamie at his day program. I drummed on his tray playfully trying to evoke one of his delightful smiles. Amber, another program participant, began wiggling in her chair, looking fiercely at me and saying something I was unable to understand. I looked to her aide for a translation. "She is saying, 'Don't hurt Jamie.'"

I was struck at that moment by the deep value in Amber's connection to Jamie. Her desire to protect him was an affirmation of humanity and compassion on a level that I had never witnessed before. Their connection could not exist if they both weren't attending an adequately staffed and funded program. These apparently helpless individuals continually pin us to the wall with the heavy weight of decisions that will affect the quality of their lives. People who work with and love individuals with intellectual disabilities will tell you: no matter how profound the disability, how pervasive the need, a soul and a spirit lives in there. It is our job to protect and nurture that spirit. There is nothing we do more important than that.

Please don't hurt Jamie.

Thank you.

Respectfully submitted,

