

Testimony, DDS Five-Year Plan Hearing, December 6, 2016

I am George Griffin's Mother.

My name is Lindsay Mathews, and I am the Mother who filed the lawsuit against the Department of Developmental Services (DDS) and defendants Morna A. Murray, and Thomas A. Dailey.

In the lawsuit, I am seeking an order barring DDS from taking away George's professional State caregivers and replacing them with highly exploited, non-skilled substitutes who are paid less than half the cost of living in CT. These workers get infrequent raises, and are forced to live as paupers while at the same time living in the richest country in the world and in one of the richest states in the country.

As the basis of my lawsuit, I refused to submit the HIPAA because I believe the practice of using private medical information for business purposes is unlawful. In fact, in the course of the non-profits shopping for contracts with the State, the only covered entity that *actually provides medical care* is the one who wins the contract.

How did we get here? How did we get to the point where there are very few resources and importance given to funding the health and well-being of those who cannot care for themselves – those who cannot even speak?

We got here because our developmentally disabled family members can't defend themselves. They are easy to attack, to steal from and to ignore. To some, they are budget cuts, line items, black numbers on a printed page.

It wasn't until I initiated a lawsuit that a flood of confidential horror stories about non-profit care began to come my way from parents, guardians and siblings with family in non-profit care. The more media work I did, the more emails and phone calls I got with more pleas for help.

One day I was out bicycling and approached a woman along with her son who was in wheel chair. Her son is in private care and our conversation revealed that she had to go to her son's group home everyday for fear that he would not get his medications on time. He couldn't talk and she was afraid that subtle clues from him would be missed or just ignored. She pleaded with me for help to get her son into State care, but the only thing I could do was to get her email address and keep her informed and supported in the hopes that she might eventually get him back into the safe harbor of State care.

A few months ago while at work, a woman who learned that I was the parent who filed a lawsuit against DDS to keep my son in State care asked me for help. Her sister's life in a non-profit group home was somewhat stable in that she

wasn't subjected to the typical revolving door of workers. Her problem was that she had to work almost full time to keep her sister's health stable including that of working as a citizen pharmacist, detective, investigator, researcher, social worker and advocate.

For families who can't be there to guard and protect a family member in a non-profit, the stress levels on marriages and family life can be devastating. Who's needs come first...the children at home, the care of an aging grandparent or the child who because of his/her handicap is forced to live in an unstable situation away from home?

This is the face of private care and just some of the negative impacts it has on families.

If they can get it, private care means they pay for it themselves. They pay for it with round the clock vigilance, worry and fear. They pay for it when the non-profit, strangled financially by the State skimps on staff and services, and they pay for it when they have to live with the fact that the safety net they always thought would be there for them is gone.

"Private, non-profit" vs. "public care." Let's stop arguing about that. We all know that the same level of care provided by well-trained, professional union workers cannot be delivered by workers paid \$12 an hour. And these lower-income jobs actually hurt the economy of our State because these workers then need public assistance for food, heat and electricity.

We demand that the State of Connecticut give us what it has always provided and maintained - a system of healthcare for our developmentally disabled citizens - a system staffed by professionally trained, well-paid workers who stay in these jobs year after year and who become like family to our children.