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Program Review Committee

HR Bill #5036

I am here today to speak for my daughter, Susan, who cannot speak for herself. She has been a resident at Southbury Training School (STS) since 1979. She is 45 years old and has Rett Syndrome, caused by a mutated gene that suppresses development. She is quadriplegic, has a feeding tube and her communication is mainly through eye gaze. She is prone to aspiration pneumonia and need a doctor's diagnosis in an immediate way. Her feeding tube is active 23 hours a day and tends to malfunction, so nurses are needed to correct the problem quickly.

Susan's disabilities put her on Level 7 of Needs Assessment (8 being most extreme).

She has visited Dr. Sasha Djukic (at Montefiore Hospital, Bronx, NY) who is a Rett Syndrome specialist. Dr. Djukic has complimented the STS staff for Susan's exceptional skin care. Susan gets a full bath everyday and is repositioned every two hours. She has never had a bed sore. Dr. Djukic sees Rett girls from many group homes, some of whose skin care she says is "pathetic".

Although she doesn't speak, experienced STS staff can interpret Susan's sounds of discomfort or pleasure. Susan's cottage is ICF/MR and therefore has an active therapeutic program. She attends a day program at Roselle School and goes on frequent outings in the community. Her cottage has residential teaching strategies, a nursing care program, inspection assessments, physical therapy and music therapy on grounds. Nurses are at her cottage daily and are experienced with G-tube maintenance. The Health Care Unit is nearby with doctors on duty.

While visiting two Provider's Fairs at STS, I spoke with several private group home representatives from Litchfield County. I gave them a check-off list comparing Susan's care with what they could offer. Two said she was too medically involved for their homes. Others answered questions with "could be developed", "doctors and nurses on call", "consults", "provide per individual", "community resource", "no experienced dentist" and "no sidewalks or courtyards wheelchair accessible". These responses were disappointing and lacked a certainty of continued quality care.

Susan's needs are extreme and complex. STS, with its multitude of resources meets her needs. Yes, per diem costs are high, but private providers will have to rely on many community resources, where costs are not born by the group home directly. I don't know how one can compare such variables.

As a cost saving measure, I am told, private provider salaries for care givers are modest, thus attracting less capable and less experienced help.

I seek assurance that Susan's care would be equal to or better than she now receives at STS and that services would not diminish over time. So far, it seems uncertain that private providers could do so.

As a 73 year old mother of a profoundly disabled daughter, I seek peace of mind that Susan's future includes at least the level of care she receives at STS.

Thank you.

*Marylyn Hendricks
Larry Hendricks*