

## **Funding life-time supports and services for developmentally disabled people**

Eileen Nicole Simon, PhD, RN

11 Hayes Avenue, Lexington MA 02420-3521, phone 1-617-512-0424

[eileen@conradssimon.org](mailto:eileen@conradssimon.org)

I have been struggling for 25 years now with the post-age-21 problems of my son who will be 46 years old on September 18. The burden and grief of autism (or PDD) only gets worse.

**SUGGESTION:** Long-term care insurance should be required for every child born in the USA, just the way automobile insurance is required for every car and driver. Insurance companies do know how to figure out how many uninsured drivers are out there, and they could do the same for children whose parents might evade a mandatory insurance law. Insurance is the American alternative to socialism and communism – and Social Security also should be privatized, for the same reason no one would want automobile insurance to be provided by the federal government. I first proposed this 8 years ago on my website [conradssimon.org](http://conradssimon.org) (under Social Responsibility)

Estate planners appear at every conference on autism, and I have been approached by people proposing that I join a group of families who pool resources for life-long care. I do not have sufficient assets to be able to join such a group. Autism has severely hindered my employment opportunities despite my education and long experience. My son is reliant upon the current public system, which stinks.

**WHAT WE ARE DEALING WITH NOW:** My son lives in a group home, but he will no doubt end up in prison after I am gone. He has served several prison sentences already – for unauthorized use of an automobile, assault and battery with a dangerous weapon (the car), and most recently for open and gross lewdness (at the upscale Charles Hotel in Cambridge MA, where he went to take a shower at the swimming pool).

What happened? The director of the group home restricted him to the house (a locked-door residence) on suspicion that he was smoking inside the house. So, my son packed clothes and his medications for a 2-day vacation from the house. It's summertime. How horrible to be restricted to a grubby group home. He had been reading a library book about John Kennedy, and said, "I just had to go see the Kennedy School of Government." He planned to stay at the Lutheran Church homeless shelter in Harvard Square, "But they don't have showers there."

My son is high-functioning. We thought he had completely recovered from the diagnosis of "mild" cerebral palsy we were given when he was 21 months of age. He started going downhill during his teens, and missed graduating from high school by just a few months.

He should be able to get a GED, and he certainly is capable of doing useful work, but the group home does nothing to help him achieve any meaningful goals, and I am despised for trying to make suggestions. I have much more to say, but am at the end of my one-page submission...