

To: Rep. Debbie Wasserman Schultz, FL. 20th and Attorney General Eric Holder

Phillip Miller, age 45, son of Mary Paulsen, Utah

Phillip has severe autism and is virtually nonverbal. As an adult, he has Obsessive-Compulsive Disorder and is still hyperactive. He is a large man and can be assaultive/dangerous when he does not get his way. I placed him at our "state institution" when he was five because of my divorce and the death of my mother; could not care for him. When he was twenty I chose to move him to a group home because I listened to the advocacy song of "normalization" and "opportunity".

His life has never been easy. There have always been unexplained injuries. He has moved from place to place and the staff turnover has been horrendous, always requiring Phillip to be the one to make the adjustment. The more Phil learned to do (??independence??) the more at risk he became as he does not understand consequences. The group home contract required Phillip to have one-on-one staffing during hours he was awake. In 2006 he was left alone in the kitchen when there was only one staff and that person had gone to attend to the other resident. Phillip's rugby shirt caught on fire at the gas stove and his back was severely burned ultimately requiring a skin graft. I cared for his burns at home for three months. When he was ready to return to care, our State bureaucracy had terminated the contract of his previous provider and wanted me to send him back to the same home with the same staff, just a different provider agency. That was unacceptable. We were able to find another provider and Phil lived in an apartment

with a staff to care for him. When the lease was terminated, we paid \$5,000 for repairs to the apartment because of Phil's damages. The "community" is no place for someone with no language. Phil cannot tell anyone what has happened to him or what he needs/wants. The staff who care for him have no understanding that his behavior is fragmented—sometimes he is an adult and sometimes he is a four-year-old. As his legal guardian, I requested that he be placed at our Utah State Developmental Center. He needs ICF/MR care with all its standards and he needs a campus to live on. I was refused. He met the statutory requirement that someone "is a danger to self and others" but our State Director had all the jurisdiction. My CHOICE was nonexistent. **Shortly after leaving his group home his fellow roommate died from malnutrition so stated the Medical Director.**

Despite the State Director's orders to keep people like Phillip living in the Community, after 15 years of saying NO, with efforts of our legislature and many concerned parents, a bill was passed to allow the legal guardian to have CHOICE. It was still a fight with our bureaucracy but Phillip is now happily living at our public ICF/MR.



Edict #1

Freedom of Choice. As provided in 43 CFR 4441.302(d), when an individual is determined to be likely to require a level of care for this waiver, the individual or his or her legal representative is: i. rmed of any feasible alternatives under the waiver, and ii. given the choice of either institutional or home and community-based services.

Edict #2

From Utah's waiver document

3.....It is, however, the individual's option to choose institutional (ICF/MR) care at any time during the period they are in the waiver.