



CALIF

Communities Actively Living Independent & Free

634 S. Spring St., 2nd Floor, Los Angeles, CA 90014

Tel. No: (213) 627-0477; Fax no.: (213) 627-0535;

TDD/TTY: (213)623-9502 Website: www.calif-ilc.org

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To whom it may concern:

My Sister and I are both disabled and have Muscular Dystrophy. We both live with our Mother who has Dementia. My sister and I use power wheelchairs and my mother uses a walker and a manual wheelchair for long distances. My sister receives SSI, SSDI and IHSS. I receive SSDI and IHSS. My mother receives Social Security Retirement and we just got her on IHSS and are in the process of appealing for protective supervision.

These past few years my sister and I have learned quite a bit about caring for our mother while dealing with our own disabilities.

1. Modifications to Homes – We just downsized my moms house. Luckily for us we had the funds to make the needed modifications. We spent about \$50,000. I realize for most people on limited funds, that is completely out of reach, but now that all the funds are gone for our family, it worries me that some other great expense will come up and we will not be able to afford it. There should be grants available for the elderly and disabled so that we can remain in our homes. I realize there is the Handy Man program here in LA County but that is capped at \$5,000. That is a drop in the bucket. When you are living with people with multiple disabilities, we need more help.
2. This past year my mother has been in the hospital several times. The ironic thing about it was that she was receiving home health care with a nurse stopping by several times a week. It seemed every time she was discharged by the home nursing company, she would end up back in the emergency room within a day or two. I think that there should be an option for the families who are caring for people with dementia to continue home nursing if the family feels it is necessary. We know our love ones better. I would dread when the nurse would tell me its time for my mom to be discharged because I knew she still needed care and she would end up in

the emergency room. They say we can appeal their decisions, but then we worry about the cost we might be responsible for if we lose an appeal.

3. Transportation – Since my mom uses a manual wheelchair and has great difficulty getting out of cars, we have had a lot of problems with transportation. I am the one with the power of attorney for my mom. I use a wheelchair too. I am her voice, so whenever she goes for any medical appointment I need to go too. Access Services is the most common transport for people with disabilities, but they require an interview appointment that can take several hours. My mom cannot do that. She is good for maybe one or two hours but, I know that it takes a lot longer than that so, I cannot get her signed up for the service.
Also, emergency transportation is greatly needed. I can call 911 when my mom is in a crisis. They will take her to the emergency room but, I have no way of getting there without help. Access Services requires 24 hours notice. I have had to roll my wheelchair 14 blocks to get to the emergency room to be with my mom when she had a heart attack. This was very dangerous for me to do, but I had no choice. California needs to invest in emergency transportation for the elderly and disabled. Some things are truly emergencies and cannot be planned for in advance.
4. As I said in the beginning, we are in the process of appealing IHSS for protective supervision for my mom. With dementia, things can change rapidly. In just a matter of days my mom went from sleeping normal hours every night to waking up every few minutes and walking our halls saying she is going to leave the house and look for her kids. Because of our disabilities, my sister and I cannot get out of bed very fast. It takes me 20 minutes and my sister much longer. When you have someone threatening to leave the house with dementia, time is of the essence. I think that IHSS should be temporarily approved even for a request for new services if they have dementia. If it turns out she is not qualified, then simply send a letter after the request is investigated and tell us the reason why. But, as of now we are doing the impossible. My sister stays up late nights and I get up early. This has had a bad effect on our health, but we have no choice. We don't want to put mom in a nursing home when she has every right to stay at home with us. It is just these unnecessary time delays that make our lives harder.

Thank you for your time,
Carrie Madden and Kristy Madden
(818)433-9707