

Needed: Independent Living for Ashly

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In July 2004, my grandniece Ashly Gambino was shot at a residence in Raleigh, North Carolina. At that time, she was barely sixteen, and the bullet burned through her spinal cord at about C2-C3.



Ashly Gambino

Her journey thus far has been tedious. Her parents were unable to cope, and she was left with just a few extraneous family members to help her reach her goal of moving back to New York, finishing her high school education and living outside of an institution.

Her first institution was WakeMed Raleigh, where she was taken after she was found at a convenience store parking lot fighting for her life. The perpetrator had dragged her to a car from the residence at the owner's demand and called 911 from the store lot. WakeMed treated her as a trauma center does, and later put her in the geriatric ward because it appeared that she would live. They would search for long-term care for her.

In October, Ashly had movement in her limbs and, because of that development, the Shepherd Center in Atlanta entered her in their spinal cord program. The Center is full of young people striving to find ways to take care of their own lives, looking for independence, and realizing that there can be life after paralysis. She had so much fun there and became determined to live a full life. However, not the life she had previously dreamed.

The Center worked with Ashly but was concerned all the while about her lack of guardianship. She remained there from January through April 2005 when I was able to find a New York facility to take her, Medicaid pending.

Ashly did not have a New York Medicaid number yet because she was still covered under North Carolina Medicaid. The Northeast Center for Special Care, Lake Katrine, New York, had room for Ashly in their Ventilator Care and Ventilator Weaning Program, and freely accepted her as she awaited her transition into New York's Medicaid program. Ashly stayed there from April until July.

It was an absolutely frightening and disgusting existence for this teenager far away from home with no way to defend herself. She was often confined to her room, but she did have great therapists working with her to help strengthen her neck muscles and to gain more movement.

Finally in July her Medicaid number came through, and The Highlands at Brighton, Rochester, New York, accepted Ashly into their Long-term Ventilator Unit. There are only two places in Rochester that will take patients who use ventilators long term: The Highlands and Unity Living Center. Unity did not feel that they had the right facilities for Ashly.

continued, page 3

Needed: Independent Living for Ashly

continued from page 1

It was a lateral move for Medicaid and they would not bear the expense, so we got together the \$2500 to move her to Rochester where at least we could visit her.

Since her move, I have been working with The Center for Disability Rights in Rochester to find housing and care for Ashly. There are other ventilator-assisted young people living on their own in Rochester, and Ashly was ecstatic to think that she could get out of the geriatric ward and live among younger people.

I have been working for more than two years trying to put all the pieces together. I meet stumbling block after stumbling block, yet all the while she encourages me. We have finally found appropriate housing for Ashly in Nunda, New York, in a newly constructed complex for people with lower incomes and seniors. The managers have gone out of their way to make one unit especially for Ashly. It has a roll-in shower, Hoyer lift ceiling track, generator, special flooring, etc.

The latest stumbling block has me reeling. Ashly could have moved into this apartment last November, but we

could not find an agency that would provide care for her.

She obviously needs 24/7 care, but it doesn't have to be private duty nursing alone. We could mix and match that care according to her daily needs. There are agencies that provide services in the area, but they are refusing to take her case because of the ventilator — she uses the LTV®950 (www.pulmonetic.com). Now Medicaid will not approve 24/7 nursing for Ashly to live alone in an apartment.

The apartment will not be held very long for her. Her goals to get to New York and to get her high school diploma have been met. Ashly wants to shop for her own food, make her own menus, eat when she is hungry, and not be at the mercy of caregivers who work by the clock and not always in her best interest. She wants what we all want: to be among people living ordinary lives, developing relationships, finding purpose and a reason to get out of bed in the morning.

Anyone with creative suggestions and solutions is welcome to contact me at donnaleel@yahoo.com. ▲

US progress in providing personal assistance services

The Centers for Medicare & Medicaid Services (CMS) requested public comment on *Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling)*. Recipients would retain control and authority over how the services are provided, who provides the services, the hours they work, and their rate of pay. Under a self-directed personal assistance services state plan option, beneficiaries could receive a cash allowance to hire their own workers to help with such activities as bathing, preparing meals, household chores and other related services that help a person to live independently. Allotments also could be used to purchase items that help foster independence such as a wheelchair ramp.

The proposed rule can be downloaded from the CMS website:

www.cms.hhs.gov/MedicaidGenInfo/Downloads/CMS2229P.PDF