



Connecticut Association of Area Agencies on Aging, Inc.

Testimony – Human Services Committee 2/28/08

Kate McEvoy, JD, Deputy Director
Agency on Aging of South Central CT, (203) 785-8533

Position

- **C4A supports Raised Senate Bill 414, An Act Concerning the State-Funded Home Care Program for the Disabled and Personal Care Assistance Program for the Disabled.**

Senate Bill 414 seeks to:

- increase the number of participants in the Connecticut Home Care Program for the Disabled (CHCPD) from 50 to 70;
- tie asset eligibility limits for the CHCPD to those for the state-funded portion of the Connecticut Home Care Program for Elders (CHCPE);
- appropriate \$1 m. for the CHCPD; and
- appropriate \$2.5 m. to increase participation in the Personal Care Assistance (PCA) Waiver by 150 persons.

Connecticut Home Care Program for the Disabled

Led by advocates from the Multiple Sclerosis Society, advocates have for some years identified a serious unmet need for case management and supportive services for individuals who have not yet reached age 65 (the eligibility threshold for the CHCPE). The legislature responded with **Section 29 of Public Act 07-2**, the DSS/DPH “implementer”, which created a state-funded pilot program with services based upon the Connecticut Home Care Program model for up to 50 individuals age 18-64.

Since the launch of the program in November, 2007, DSS has worked with the three Access Agencies for the Connecticut Home Care Program for Elders to identify, screen and provide care management and services to program participants. Care management staff at the Agency on Aging of South Central Connecticut (AASCC) has already

enrolled nine clients in this important new pilot program, the majority of whom has a diagnosis of MS. Please find attached a recently released article drafted by AASCC's Communications Specialist that profiles a program participant.

As individuals are already being waitlisted for this program, additional funds are needed to support expansion. Also, for the sake of consistency, asset limits for the CHCPD should be tied to those that are used for the CHCPE.

Personal Care Assistance Waiver

Over time, and in recognition of increased interest in self-directed care options, Connecticut has created new vehicles through which individuals can receive their home care services on a more flexible and individually-tailored basis. These include the Personal Care Assistance Waiver (**PCA Waiver**) and the Personal Care Assistance Pilot (**PCA Pilot**).

The Personal Care Assistance Waiver (**PCA Waiver**) is a 1915(c) Medicaid waiver that was first approved in 1996. Historically, the PCA Waiver served individuals age 18-64. In 2006, the Connecticut legislature removed the upper age limit. Individuals who meet income and asset guidelines for the program may qualify to hire one or more personal care assistants to help them in bathing, dressing or other needed tasks. PCA's are hired and managed by the individual. A third-party contractor handles payments. Currently, 748 individuals are actively participating in the program, 124 are pending eligibility and 70 are waitlisted. An additional appropriation is needed to support more of the people who are on the waitlist.

The **PCA Pilot** was established in 2000 to serve up to 50 individuals statewide. This program, which enables participants of the Connecticut Home Care Program for Elders (CHCPE) to hire and manage the schedules of their own helpers, was intended to serve younger individuals with disabilities who were aging into eligibility for the CHCPE, as well as older adults whose needs could not be effectively met through home care agency-based care plans. Over time, the PCA Pilot has been expanded. In the 2006 legislative session, the number of slots was increased to 250 statewide, and in 2007, the cap was entirely removed.

The new Connecticut Home Care Program for Disabled (CHCPD)

In Detail

The new Connecticut Home Care Program for Disabled (CHCPD) pilot program is designed to help up to 50 persons ages 18 to 64 with neurodegenerative diagnoses.

Administered by the State Department of Social Services, this state-funded pilot program provides care management and supportive services.

Who is eligible?

- Those who are inappropriately institutionalized
- Those who are at risk of inappropriate institutionalization and who require assistance in three or more of these areas: bathing, dressing, toileting, transferring, eating/feeding, meal preparation or medication administration, and/or have need for daily supervision and/or a cognitive deficit.

Please note: Those who are participating in or are eligible for Medicaid do not qualify for this program.

What are the financial eligibility guidelines for this program?

- An individual may, in 2008, have assets of no more than \$20,328.

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Pilot Program Is 'Life Saver' For Connecticut Resident

We all live our fast-paced lives and take the simple things for granted. Things like getting in and out of bed, going to work, running our daily errands, taking care of the kids and making dinner. For Connecticut resident Brenda Curran, five years ago, life was very much like everyone else's, fast paced and very productive. "I always had a very busy life. My husband and I were always involved in youth groups, work, musical activities, a totally normal life," said Brenda. Then one day a simple "twinge" in Brenda's leg dramatically changed everything. At first she ignored it, thinking it was nothing, but as time past this "twinge" worsened to the point where Brenda's leg was more and more compromised.

"Things developed at such a slow pace that I just learned to adapt over time. Then I got to the point where I could not get my leg into the car. I grabbed one of my husband's belts and I would lasso it to my leg and hoist my bad leg into the car".

After countless visits to doctors, and more tests than anyone can image - the diagnosis was Multiple

Sclerosis (MS). "The day I was diagnosed I will never forget," said Brenda. 'There are a lot of pamphlets in the front of the office on MS. Please take them, read them, get on the internet and learn,' the doctor said.

Brenda wanted to learn all she could about MS, and believed that the more she knew, the better she could take care of herself. "I believe knowledge is power. The first book I picked up on MS listed 20, symptoms. I had 18 of them," said Brenda.

Within a year of the diagnosis, instead of heading off to work each day and caring for her family, Brenda had great difficulty leaving home and was barely able to move. Fast forward to October 2007: Life for 60 year old Brenda Curran had become even more challenging. The living room that was once a place for the family to gather had now become a place in which Brenda was a prisoner. Daily she waited for her husband of 35 years to come home from working one of three jobs, to attend to her needs. Simple tasks like getting up, using the rest room, making food, and getting a drink

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Travis Barker, Care Manager at the Agency on Aging of South Central Connecticut (left) with Brenda Curran (right). "This is such a wonderful program, it has changed my life."

Pilot Program Is 'Life Saver' For Connecticut Resident

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were no longer a way of life for Brenda. She depended completely on her husband for everything; he was her only care provider.

As Brenda's physical health declined, her concern for her husband's health increased. "My biggest concern and worry for a very long time was my husband the caregiver. One person cannot do it all, and he was doing it all to the point where I was fearful for his health. He was spending all his time taking care of me, and the household chores."

"My physical health was not good because there needed to be more hours in a day for him to be able to do everything that had to be done. So things just had to be put off."

The future for Brenda seemed, until recently, to be decidedly grim. It seemed inevitable that as her condition worsened, she could not remain at home. Her husband, who had cared for her to the best of his ability for many years, just could not do it anymore - he was in desperate need of help - the only apparent solution was a nursing home.

Brenda struggled both mentally and physically trying to avoid going to a nursing home. "When I would encounter an obstacle I would say to myself 'Bren you have to figure something out because you're not going to end up in a nursing home'.

In 2003 and 2004 because of infections in Brenda's legs she found herself in a nursing home on two occasions. This was less than ideal. For Brenda that ideal room temperature inside the nursing home was always too high. "With MS heat is your enemy it will take your body and totally shut it down. It is such a horrible feeling because it is totally out of your control. There is nothing you can do."

"When I was in the nursing home I got to the point where I could not even lift my arm because of being overheated. At times I was so warm

I was not be able to even get up. So the nursing home was no place for me."

Just as it appeared that all hope was lost, a tiny light appeared in front of Brenda, a light in the form of a pilot program called the Connecticut Home Care Program for Disabled (CHCPD). This new state-funded pilot, which is administered in South Central Connecticut by the Agency on Aging, was the miracle that would allow Brenda to remain at home, to get the care she needed, and to give Brenda's husband some relief from caregiving.

November 2007 was the month where Brenda began to live life again. "I cannot say enough about the MS Society. Susan Raimondo, from the MS Society, was the first person with whom I was in contact. Susan, who should be put up for sainthood, told me that Governor Rell was going to be signing a new bill for people with disabilities."

After many years of uncertainty, things were now moving very fast for Brenda. "On a Friday of that week the Governor signed the bill, and on Saturday my husband received an email from Susan with a telephone number to call. Susan wanted me to be the first to call on Monday morning. I then received a telephone call from the Agency on Aging. People from the agency came to my house, I signed the paper work and the following Monday I started to get help. It was just amazing."

Travis Barker, Care Manager at the Agency on Aging of South Central Connecticut, met Brenda in November 2007. Travis helped to assess Brenda's needs and now coordinates her services. "We have a tight budget to work with" said Travis. "We look at all her needs carefully so we can give her as much help as we possibly can. Brenda is a fighter and she has fought very hard to get where she is today. Being able

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The new Connecticut Home Care Program for Disabled

In Detail

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- A married couple, in 2008, assets may have assets of no more than \$30,492.
- Some participants in this pilot program whose income exceeds a certain level may be asked to contribute toward the cost of their care.

Please note: The asset amounts for individuals and couples are as of January 1, 2008, asset levels may change during 2008.

"This initiative is especially important as we expand our home care services to people with disabilities beyond the traditional age group of 65 and up," said Governor Rell. "For years, the Connecticut Home Care Program for Elders has been a tremendous help in maintaining quality of life for over 13,000 senior citizens. The new pilot program will start bringing the same benefits to our younger population with disabilities."

Services that can be provided by the CHCPD program may include:

- nursing
- home health aide
- physical, occupational and/or speech therapies
- companions

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The new Connecticut Home Care Program for Disabled

In Detail

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- homemaking
- home-delivered meals
- attendance at an adult day center
- chore services
- transportation
- minor home modifications

An individual plan of care is developed based on the needs of each participant.

"For years, Connecticut has been a leader in services to help people with disabilities live in the community," said Governor Rell. "We have worked with the federal government to use Medicaid dollars for community-based programs for elders, people with profound disabilities who need personal care assistance for daily living activities, and people with acquired brain injuries, to name a few examples. However, there are other citizens with disabilities whose needs have not been covered or met completely. The result is ongoing risk of nursing facility placement or the inability to leave a nursing facility. The new Connecticut Home Care Program for Disabled will begin to fill an unmet need for the 18 to 64 population struggling with neurological disease."

The goal is for expansion

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to provide for and help someone like Brenda is an amazing experience."

According to Susan Raimondo, Community Programs Director with the Connecticut Chapter of the National Multiple Sclerosis Society, advocacy for the pilot has evolved over four years from a small group of activists to include support from over 25 organizations. Grassroots volunteers worked hard during this time to make contacts with legislators and the Governor.

"The cooperation and cohesiveness between the aging and disability communities in coming together to support this pilot is phenomenal," said Susan.

"The Connecticut Department of Social Services was very receptive to working with us. When the funds were appropriated in 2007, its Alternate Care Unit was enthusiastic about the opportunity to start a new pilot," said Susan. "We have the highest praise and appreciation for everyone at the Department of Social Services who has been involved, lead by Kathy Bruni, and for the Access Agencies for all of their hard work in getting the program off the ground."

The National MS Society's Care Management and Financial Assistance programs work with a number of individuals who are facing very difficult situations. "It can be amazing to learn about the challenges that individuals have dealt with on a daily basis," said Susan.

"One of my main goals, to expand home and community-based services to individuals with MS and other disabilities, is being fulfilled with this program."

For years, Susan has seen many individuals whose only option for care as their disability worsened was to move to a nursing home. "The CT Home Care Program for the Disabled can now provide a choice so that individuals can remain in their own homes and are not forced to move to a nursing home automatically

when their disabilities have progressed," said Susan.

"Often a person can become angry and frustrated at their situation and they may take it out on us or the people who are trying to help. That could not be further from the truth in our contact with Brenda. Ever since we met Brenda, she has been delightful, appreciative, pleasant and resourceful."

The program has really hit home for Brenda. "This is such a wonderful program, it has changed my life," said Brenda. "Since 2003, I have not been able to do anything. I never realized how lonely I was until I started having help come to the home."

For Brenda, there was now a tremendous difference in her life. "The quality of my life, even as far as being clean, to sit here and not even be able to brush my own teeth or wash my hair, now things are very different and it is tremendous."

Meals are a welcome service. "To have a warm meal is now such a treat because before there was just not enough time for my husband to get everything done. Sometimes he would have to rush out of here. He would get to work and say 'oh my God did I leave her water, did I leave her food?' "There were even days when I could not even get my medication until my husband came home."

A good example of Brenda's improved physical health is the overall condition of her legs. "I wear compression socks on my legs that need to be changed daily. Previously, we were lucky if we got them changed once a week; consequently my legs were turning a dark brown or black. Now with this program and the home health aide, everything is taken care of. My skin is completely normal again."

Now instead of feeling thoughts of depression, Brenda feels happy. "I have not been unhappy in the man-

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ner I once was. My entire inner being has changed, I can smile. I was pretty miserable."

At times Brenda felt that she would take her frustrations out on her husband. "You always take things out on the one you love. This man (my husband) has done so much for me it is just unbelievable. I love him to pieces and I am so thankful he is part of my life and he has done this for me. This program has just helped in every aspect of our lives."

Where does Brenda believe she would be without this program? "Without this program I would have been put in a nursing home. The scary thing is that because of my experiences in nursing homes I knew I could not go back. The thought of going back into a nursing home would put me into deep depressions. I am the same person I was 5 years ago, it is just that my mind tells my body to do things and it just can't do them."

With help from the program, Brenda is now securely situated in her own home. She spends every Saturday morning now speaking with her grandchildren who live in Vermont. "I spend four hours with my grand children on the speaker phone. It starts with breakfast. We interact like I am sitting there with them. They go into their kitchen and say, 'ok Grammy, I want waffles for breakfast, I want bananas and cereal', it's a wonderful, experience for me."

What does the future hold for Brenda Curran? She hopes that she will be able to cook, wash dishes, work on the computer, and work on her crafts. "I have been in this chair for more than a year. My ultimate goal is to get more physical therapy and get strong enough to get out of this house and to really start living."

With the help of this program and Brenda's drive and determination, she strives to get back her independent life. "I am going to become that independent person again. I am

not going to stop until I achieve my goals. I eventually hope to get back to work, probably some sort of work-at-home position. I have been desperately saving up for a lap top computer, but with all the medical expenses it has been difficult saving money."

Brenda recently wrote a letter to Governor Rell, and told her how this program has changed her life. "I wanted the Governor to hear from the perspective of a person who this program is helping. I wanted her to know the difference that the program has made in my life. I wanted her to be aware of how well the money was being spent. Mostly I wanted her to know that deep down inside, if it were not for this program I would have ended up in a nursing home."

Brenda not only wanted the Governor to be able to link a face to the issue, but also to let Governor Rell know that she could now live a vital life at home. "I think people need to put a face to the problem and people need to know these are human beings and these are their."

"There are so many people to thank for helping to advocate for this pilot", said Susan Raimondo. These include the CT Association of Area Agencies on Aging, the CT Commission on Aging, the Long Term Care Advisory Council, the Connecticut Women's Health Campaign, the CT Elder Action Network, AARP, the Alzheimer's Association, Governor Rell, OPM Secretary Robert Genuario, DSS Commissioner Michael Starkowski and Kathy Bruni, Manager of the Alternate Care Unit of DSS; and numerous committed legislators.

With the help of the CHCPD and a number of very caring individuals, Brenda Curran has a new lease on life and is optimistic for the future.

"I tell my grandson, 'Grammy is going to dance with you at your wedding'".

- Story by Don Bamberg

The new Connecticut Home Care Program for Disabled

In Detail

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of this program. "As a pilot, the Connecticut Home Care Program for the Disabled is serving a small population. Our goal is to expand the program to serve more individuals," said Susan Raimondo, Community Programs Director, National Multiple Sclerosis Society Connecticut Chapter.

Susan hopes that during the 2008 legislative session, legislators will increase program funding to \$1,000,000; and amend the law so that asset limits match those under the State-funded part of the Connecticut Home Care Program for Elders.

For more information, contact the Agency on Aging of South Central Connecticut at 203-752-3040 or 888-811-1222. Or The National Multiple Sclerosis Society 800-344-4867.

To apply for the program, call 1-800-445-5394 and choose option 4. Application forms are also available on the DSS Web site: www.ct.gov (click: Quick Links, State Agencies, Department of Social Services).

- Story by Don Bamberg