

***Long-Term Services, Supports and Housing:
Consumer Input***

July 31, 2012

3:00 - 4:15 PM Eastern

Call-in number: 800-745-9830

Conference Call Participant Agenda

- **Welcome and Introduction**

Sara Cirba, Advocacy and Development Associate

- **Purpose of call: Consumer Perspective on Quality Report**

Sara Cirba

- **Instructions for responding to questions**

Sara Cirba

- **Questions**

Facilitated by Robyn Grant, Director of Public Policy and Advocacy

1. How is your home care paid for?
2. What are some things you like about receiving services and care in your own home instead of a nursing home?
3. If you could change anything about the home services and care you receive, what would you change?
4. Do you feel that you get enough hours of care in your home?
5. What kind of training do you think workers should have in order to do their job well?
6. Does your worker have the flexibility they need to help with all the things you need help with?

7. Would it be helpful to create a written plan for your care with your worker?
8. If you have a problem with your care and services, who do you turn to for help?
9. Would you be in favor of the government creating a home care ombudsman – that is, a person or people that consumers receiving home care and services, like yourself, could turn to for help?
10. Do you think the government is involved too much, too little or just the right amount in helping people to get quality home care? Please describe.

- **Participant Question and Answer**

Robyn Grant

- **Consumer Input Council**

Sara Cirba

- **Consumer Voice Action Network**

Robyn Grant

- **Wrap up/closing remarks**

Sara Cirba

LTSS Options at Home and in the Community

March 2012

Consumer Fact Sheet

What are long-term services and supports (long-term care)?

Long-term services and supports (LTSS) are the type of assistance people need to carry out the tasks of every day life and live as independently as possible.

These tasks are usually divided into two categories:

- Self-care tasks such as bathing, dressing, eating, getting to and from the toilet, getting on and off the toilet, performing personal hygiene, moving around and moving to/from a bed or chair to a wheelchair. These tasks involve caring for and moving your body. They are often called “activities of daily living.”
- Tasks that help you live independently and conduct the business of every day life, such as housework, preparing and cleaning up meals, shopping and running errands, taking medication and managing money. These tasks are usually referred to as “instrumental activities of daily living.”

Another name for long-term services and supports is long-term care.

What are the most common long-term services and supports at home and in the community?

There are many services and supports that are provided in a person’s own home or in their community.

Examples include:

At home

- Personal care: assistance with activities of daily living provided through an agency, an attendant hired by the consumer, or by family or friends.
- Personal emergency response system: An electronic device that allows a person to call for help in an emergency.
- Homemaker: Assistance with household tasks such as dusting, vacuuming, making and clearing up meals, doing dishes, grocery shopping and running errands.
- Environmental modification / home modification: Adaptation of an existing home to make it more accessible and / or safer and to help make it easier to get around and do daily activities. Examples include adding ramps, hand rails, grab bars, lever handles on doors, lifts and wider doors.
- Respite care: Short-term, temporary supervision or care of an individual when the primary caregiver cannot be there or needs a break or “time off” from care giving responsibilities. Can include someone coming into your home (companion services), adult day services or a stay in a nursing home or an assisted living facility.

In the community

- **Adult day services:** Social, recreational and therapeutic activities provided in a community-based program for adults with physical, mental or cognitive impairments. Some programs may also provide health and medical related care, such as medical monitoring and medication administration. Other types of adult day services are mental health day treatment - a community-based, coordinated set of individualized treatment services to individuals with mental illness and day habilitation - assistance to individuals with developmental disabilities or brain injury to develop or maintain socialization and self-help skills.
- **Senior centers:** A center in the community that provides a variety of services including nutrition, recreation, health, social and educational services and information and referral services.

Who uses LTSS?

Older adults may need long-term services and supports because they have developed one or more chronic conditions, like arthritis, that make activities like dressing or taking a bath more difficult. People of any age with a disability may also need LTSS.

How can LTSS help?

Here are two examples that show you how LTSS can help people stay in their own homes:

1. Frank Conner is 85 years old and has Alzheimer's Disease. He lives at home with his wife, Edna, who is 79. Frank needs to be monitored at home because he accidentally started a fire in the kitchen when no one was with him. Edna used to take Frank with her when she ran errands, but now he wanders away the minute she isn't looking. Frank is requiring more and more assistance with getting dressed, shaving, and brushing his teeth. This is becoming increasingly difficult for Edna, who is getting worn out. In addition, she has reached the point where she just can't bathe her husband by herself anymore.

LTSS: Edna finds an adult day services center near their house that Frank can attend three days a week. This gives her some time "off" from watching him and the opportunity to run errands, go to appointments or just rest. She also arranges with a home care agency to have an aide come in the morning and evening to get Frank ready for the day or to go to bed at night and to give Frank a bath twice a week.

2. Alice is 52 years old and has multiple sclerosis. She lives on her own and has taken care of herself for years. Now her MS has progressed to the point where she needs assistance with most self-care tasks and with household chores. Alice uses a wheelchair because she is no longer able to walk. Alice can prepare simple meals, but can't wash the dishes or pots and pans afterwards. She likes to grocery shop, but can't do it by herself.

LTSS: Alice hires 2 personal care attendants, one who helps her during the week and another who comes in on weekends. The attendant gets her out of bed in the morning and either helps her take a shower or gives her a bed bath. The attendant then helps her get dressed, including putting her brace on, fixes breakfast and does light housekeeping. The attendant then leaves after making sure Alice has what she needs to fix her own lunch. She returns in the evening to wash the dishes, straighten up, go for a long walk with Alice and get her ready for bed. Once a week they go grocery shopping together.

How do you find out what's available in your state?

The best and easiest way to learn what services and supports are provided in your state is to contact:

- **The Eldercare Locator:** This is a free national service that provides written information about LTSS in general and connects you to resources in your own community, including the Area Agency on Aging nearest you. The Area Agency on Aging is a nonprofit organization that connects older adults, and in some cases younger persons with disabilities, with information about the type of services available in their community or region. To contact the Eldercare Locator call 1-800-677-1116 or go to www.eldercare.gov.
- **Centers for Independent Living (CILs):** CILs are grassroots, advocacy-driven organizations run by and for people with disabilities. One of a CIL's core services is to provide disability-specific information and referral services. To locate a CIL near you, call 1-877-525-3400 or go to www.virtualcil.net.
- **The Department of Veterans Affairs:** The VA offers a range of services to veterans who need long-term care. For information and resources, contact the social work department of any VA Medical Facility; call 1-877-222-8387, or visit www.va.gov/geriatrics/.

The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings

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July 2012

Join the Consumer Voice Action Network!

What is the Action Network?

The Consumer Voice Action Network is a way to make a difference in the lives of people receiving long-term care at home, in assisted living or in nursing homes. The Action Network allows you to advocate easily and effectively for quality long-term services and supports.

As a member of the Consumer Voice Action Network, you will receive:

- Breaking news, updates and newsletters to keep you informed of national and state policy developments in long-term care
- Opportunities to take action
- Tools that will help make your advocacy easier, like the ability to contact your members of Congress (and other elected officials) directly through our website

Legislators pay attention to calls, letters and e-mails they get on a particular issue if they come from their constituents. Regulatory agencies seek public comments. Add your voice to the voice of others!

How Can I Join the Action Network?

Joining the Consumer Voice Action Network is free. It's also easy. You can sign up to be a part of the Action Network by:

- Registering at: https://wfc2.wiredforchange.com/o/8641/signup_page/action-network
- Calling Sara Cirba at 202-332-2275 x221

The louder our voice, the stronger our advocacy.

Join the Consumer Voice's Consumer Input Council!

July 2012

What is the Consumer Input Council?

The Consumer Voice is launching a brand new Consumer Input Council as a way for consumers receiving services and supports at home to stay involved and informed on long-term care issues. By joining the Consumer Input Council, you will have the opportunity to regularly provide Consumer Voice staff members with feedback about your experiences with home care. Your information will help guide the Consumer Voice in its policy work. In addition, you will receive regular policy and advocacy updates and opportunities to take action yourself.

How Can I Join the Consumer Input Council?

If receive long-term services and supports at home and would like to be a part of this council, please contact Sara Cirba at scirba@theconsumervoice.org or at 202-332-2275 x 221.

When is the First Meeting of the Consumer Input Council?

The first meeting of the Consumer Input Committee will take place in October of 2012. You will be notified of an exact date and time closer to the meeting date. You will also be notified of the theme for the phone call and what topic areas we'll be covering.

**We hope you join the Consumer Input Council and
look forward to hearing from you in October!**