

Quality Care, No Matter Where: Consumers for Self-Advocacy

Aging in America Conference

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The National

CONSUMER VOICE

for Quality Long-Term Care

formerly NCCNHR

- o A non-profit, consumer-driven advocacy and membership organization
- o Founded by in 1975 by Elma Holder as the National Citizens' Coalition for Nursing Home Reform (NCCNHR) because of public concern about substandard care in nursing homes
- o Mission: to represent consumers at the national level for quality long-term care, services and supports
- o The leading national voice representing consumers in issues related to long-term care, so consumers are empowered to advocate for themselves
- o Primary source of information and tools for consumers, families, caregivers, advocates and ombudsmen to help ensure quality care for the individual



www.theconsumervoice.org



The National Long-Term Care Ombudsman Resource Center

- Provides support, technical assistance and training to the 53 State Long-Term Care Ombudsman Programs and their statewide networks of more than 1,000 regional and local programs that utilize more than 8,000 volunteers
- Seeks to enhance the skills, knowledge and management capacity of the state programs to enable them to handle residents' complaints and represent resident interests (individual and systemic advocacy)
- Funded by the Administration on Aging, the Center is operated by the National Consumer Voice for Quality Long-Term Care

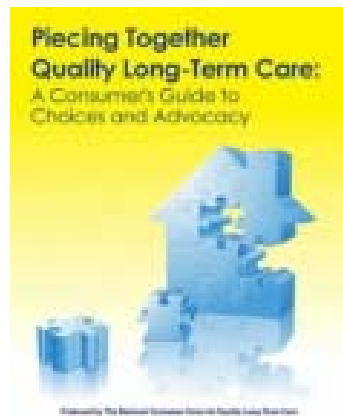
www.ltcombudsman.org

Quality Care, No Matter Where: Consumer Guides for Self-Advocacy

- One-year initiative funded by the Milbank Foundation for Rehabilitation
- Project need
 - Shared need among the elderly and individuals with disabilities for a range of *quality* long-term care services and supports (LTSS)
 - Shared daunting and overwhelming task to navigate a fragmented and complicated LTSS system
 - Many consumers and families don't know what the LTSS options are, what to look for, how to work with providers to get good care, or what to do should problems arise
 - The elderly and people with disabilities may not end up with the care option that is best for them or may suffer from sub-standard care

Initiative Goals

1. Empower people with disabilities and older adults to advocate for quality LTSS across settings
2. Strengthen citizen advocacy groups (CAGs) that work on behalf of LTSS consumers
 - CAGs are non-profit organizations that advocate for quality LTSS at the local, regional or state level
 - Consumer Voice has a long-standing relationship with CAGs and many are members of the Consumer Voice



National Consumer Guide

Piecing Together Quality Long-Term Care: A Consumer's Guide to Choices and Advocacy

- Educates people with disabilities and older adults about LTSS options so they can make informed decisions
- Empowers consumers to be self-advocates for quality LTSS
- Includes tips from consumers and information and resources to assist people currently living in nursing homes to move back into the community
- Numerous formats for increased accessibility

Online Accessibility

- A primary objective of this initiative was to make the national guide accessible on the Internet for individuals with disabilities
- The guide is available on online in various formats, including:
 - HTML
 - PDF
 - Audio Portions
 - Hardcopy (available for purchase to cover printing costs)

<http://www.theconsumervoice.org/piecing-together-quality-long-term-care>

Online Accessibility Continued

- The guide's microsite tests several ways to make the national guide accessible for individuals with disabilities. Some of the way we hope to have accomplished this are:
 - Different formats
 - Allowing the user to change both the color of the site's background and the color of text
 - Suggesting ways to increase or decrease the font size using a number of different Internet browsers
- However, this process is ongoing, and we welcome input on your ideas about how to improve this site

PIECING TOGETHER QUALITY LONG-TERM CARE

A Consumer's Guide to Choices and Advocacy

Access the guide in the following versions:

[PDF](#)[HTML](#)[AUDIO FILE](#)[ORDER HARD COPY](#)

ABOUT THE GUIDE

Almost all of us will need some assistance with the tasks of everyday life at some point in our lives. This type of assistance is referred to as "long-term services and supports" or "long-term care." This guide is designed for you (or your advocate), the individual who is currently receiving or who may in the future receive long-term services and supports - the purpose of this is to inform you about your options for long-term services and supports. Its goal is also to empower you - through education - to effectively advocate on your own behalf.

This guide is part of a project led by the National Consumer Voice for Quality Long-Term Care, and funded by the Milbank Foundation for Rehabilitation, to empower people with disabilities and older adults to be self-advocates for quality long-term care, while strengthening long-term care citizen advocacy groups that work on behalf of long-term care consumers.

SURVEY

Please take this quick survey to tell us how and if the guide helped to inform and empower you or someone you know.

[Take Survey](#)

[Introduction](#)

[Finding the Right Road](#)

Chapter 1: [What are "Long-Term Services and Supports?"](#)

[Person-directed or person-centered care/services](#)

[Chapter 1 summary](#)

Chapter 2: [What are Your Options for Long-Term Services and Supports?](#)

Chapter 3: [Home and Community-Based Services and Supports](#)

[Chapter 3 summary](#)

Chapter 4: [The "Home" in Home and Community-Based Services: Housing Options](#)

[Living with a family member](#)

[Subsidized housing](#)

[Supportive housing](#)

[Accessible housing](#)

[Senior housing](#)

[Affordable housing](#)

[Chapter 4 summary](#)

Chapter 5: [Housing Rights](#)

[Your rights](#)

[Overcoming barriers to obtaining affordable, accessible housing](#)

[Chapter 5 summary](#)

Chapter 6: [Long-term Care, Services and Supports in Residential Settings: When 24-Hour Nursing Supervision/Care is not Needed](#)

[Chapter 6 summary](#)

Tips for Making Documents More Accessible

- If possible, have a large-print option available.
 - According to the American Council for the Blind, many large-print readers recommend printing in 18-point type. However, 14-point type is considered acceptable.
- Don't use columns.
- Explain any images in the document clearly.
- Left justify the text if possible. This creates consistent spacing between letters and is easy to track visually.

Tips for Making Documents More Accessible

- Consider using block style paragraphs.
- One-inch left and right margins are recommended.
- Avoid printing on glossy paper; it may cause a glare. Consider printing on off-white page to get an optimal contrast.
- Do not center text.
- Set line spacing to 1.5 line.

Low/No-Cost Communications Tools

- **Google Groups** (www.googlegroups.com)
 - User-friendly listserv and discussion group functions to help users network, access information and communicate
- **Google Analytics** (www.google.com/analytics/)
 - Provides information and data about website traffic & marketing effectiveness
 - i.e. how many people visit your website, which pages are most visited, common searches, geographic location of users
- **Doodle** (www.doodle.com)
 - Schedule a meeting by sending participants an e-mail or a link to an online survey that collects availability for specific dates and times

Low/No-Cost Communications Tools

- **Constant Contact** (www.constantcontact.com)
 - E-mail marketing campaigns for events
 - Online surveys
 - Free 60-day trial
 - Pricing plans starting at \$15 per month
- **Tech Soup** (www.techsoup.com)
 - Provides nonprofits with free technology information, resources and support
 - TechSoup Stock, where nonprofits can purchase donated and discounted technology products

State Consumer Guides

- CAGs in Kansas, North Carolina and Virginia received funding (through an RFP process) to develop and promote state-specific guides with technical assistance and support from the Consumer Voice
- Educate people with disabilities and older adults about their options for long-term services and supports so they can make informed decisions
- Empower consumers to be advocates for quality long-term care
- Include information and resources to assist people currently living in nursing homes to move back into the community

Other Initiative Components

- “How to” document
 - To help CAGs and other consumer organizations across the country produce and disseminate their own state guides
 - Includes information from funded CAG summary reports and Consumer Voice interviews with funded CAGs
- Qualitative and quantitative evaluations to determine material usefulness, accessibility, and increase in consumer knowledge
 - National guide
 - State-specific guide
 - Website

Stronger CAGs

- Many CAGs struggle to operate with very limited staff and/or volunteers and funding
- The Consumer Voice worked within and among our network – we provided CAGs with financial and technical resources to carry out work to strengthen their organizations and the work they do for and with LTSS consumers
- In turn, strengthened CAGs can lead to consumers who are better educated about LTSS options and resources and more empowered for self-advocacy

Peer Empowerment

- Many consumer LTSS guides are designed to help adult children with their aging parents and are often written by health care professionals
- Few publications are geared to both older adults and persons with disabilities and are written from the consumers' viewpoint
- Consumer guides are written from the consumer perspective and include practical, concrete suggestions and tips directly from LTSS consumers
- Educates people about LTSS options so they can make informed decisions
- Empowers consumers to be advocates for quality LTSS

Aging & Disability Community Partnerships

- Built a bridge between the aging and disability communities to create a strong, unified consumer voice
- Project materials outreach to older adults *and* individuals with disabilities
 - National guide developed and implemented with support from:
 - Reviewers from organizations in aging and disability communities
 - Advisory council of current LTSS consumers (older adults and persons with disabilities), family members and ombudsmen
- Guides disseminated through relationships with aging and disability organizations and to people with disabilities in the three states
 - i.e. Funded CAGs were encouraged to reach out to a minimum of certain disability groups in their state (CIL, The Arc, etc.)

Consumers for Quality Care, No Matter Where

- Three-year initiative launched in October 2010
- Expand the national grassroots consumer advocacy network to focus on issues faced by LTSS consumers in non-nursing home settings
- Build a strong consumer voice to advocate for well-coordinated, accessible, quality LTSS in HCBS
- Pilot projects in five states to:
 - Identify barriers faced by consumers in accessing quality HCBS
 - Develop strategies to address public policy issues
 - Develop models of consumer engagement related to HCBS
- Consumer perspectives on quality HCBS report with policy recommendations
- National training opportunities for consumers and advocates
- Website with a story-sharing feature and advocacy tools and resources for achieving quality care

Additional Information

- The National Consumer Voice for Quality Long-Term Care

www.theconsumervoice.org

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- National Long-Term Care Ombudsman Resource Center (NORC)

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