Supporting Consumers Who Transition Out of Nursing Homes

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NLRC

Providing Legal Support to the Aging Advocacy Network

- http://www.nlrc.aoa.gov/
- Collaboration developed by the Administration for Community Living/ Administration on Aging between the National Consumer Law Center, National Senior Citizens Law Center, American Bar Association Commission on Law and Aging, Center for Elder Rights Advocacy, and the Center for Social Gerontology
- See upcoming trainings, conferences, and webinars
- Request a training
- Request consulting
- Request technical assistance
- Access articles and resources

Presenter – Sara Cirba

- Joined the Consumer Voice in May of 2012 and currently serves as the Associate of Advocacy and Development. In her role she supports the Director of Public Policy in expanding support for and engaging advocates in the implementation of the Consumer Voice's public policy and advocacy agenda, as well as supporting the Executive Director on fundraising activities to expand financial support for the Consumer Voice's work.
- Prior to joining the Consumer Voice, Sara completed a prestigious legislative fellowship in the New York State Senate where she was instrumental in creating the NYS Bipartisan Pro-Choice Legislative Caucus.
- Sara graduated cum laude from Ithaca College in 2005 with a B.S. in communications and a minor in legal studies. Sara also has a Juris Doctorate from Albany Law School and graduated with a health law concentration in 2010.

Presenter – Amity Overall-Laib

- Served as a local long-term care ombudsman in Texas for six years advocating for residents in 65 nursing homes and 130 assisted living facilities in a 12-county region.
- During her tenure in Texas, she lead the formation of the Gulf Coast Culture Change Coalition, resulting in two free conferences for long-term care consumers, providers, advocates and regulators promoting Culture Change practices and has presented during local, state and national conferences.
- She also had the pleasure of representing fellow local ombudsmen on the Board of Directors for NALLTCO (National Association of Local Long Term Care Ombudsmen).
- Amity was also previously a consultant to NORC. Amity has a master's degree in sociology from the University of Houston.

The National CONSUMER VOICE for Quality Long-Term Care formerly NCCNHR

SUPPORTING CONSUMERS THAT TRANSITION OUT OF NURSING HOMES

What Consumers Say

Long-Term Care Ombudsmen: Supporting the Consumer

Wednesday, May 28, 2014

The National CONSUMER VOICE for Quality Long-Term Care formerly NCCNHR

WHAT CONSUMERS SAY

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Background & Overview

- The National Consumer Voice for Quality Long-Term Care is a national, non-profit organization based on Washington, D.C. that advocates for people receiving care and services at home, in assisted living or in a nursing home.
- Discussion of *Nursing Home Transitions in California* report.
- How the Long-Term Care Ombudsman Program can support consumers who transition.

California Consumers for Quality Care, No Matter Where

- **Focus:** Nursing home transitions
- **Goal:** To identify ways in which the transition process could be improved
- **How:** Interview consumers who have transitioned

How we found consumers

- California Advisory Council connected us to the California Community Transitions Program (CCT)

- CCT contacted transition coordinators who identified clients who gave their permission to be contacted
  - Consumers were both older adults and younger persons with physical disabilities

Interview Focus

- Their experience with the transition process
- Their adjustment to living in the community
- Their recommendations for improving the transition process

Their experience with the transition process- Mostly very good!

ANNE

- The transition coordinator explained what to expect during the process. The coordinator helped with hiring caregivers by selecting several for Anne to interview and also assisted her in looking for housing. In addition, the coordinator picked out furniture for her as well as linens and towels.

ROBERTA

- The transition coordinator found the apartment for her, furnished it and got her a phone and set it up. The coordinator took her shopping for food and to fill her prescriptions. The day of the move, the coordinator helped her take her boxes to the apartment.

But not always…

KATE

- She needed to make phone calls (e.g. about apartments), but finding a phone in the nursing home where she could speak privately was difficult.

- She needed to go to a number of places to look at apartments, get a copy of her birth certificate because she needed an ID, pick up a letter saying how much money she was getting, etc. She used the Access bus, but transportation was expensive and she had to spend her own money for the rides.

- Someone mistakenly ordered her a manual wheelchair instead of a power wheelchair.

Their adjustment to living in the community

OVERALL: IT FELT WONDERFUL !!!

- **WILLIAM**
  - Said he “has a life again” and feels like he’s “alive again.” He said that the nursing home “sucked all the life out of him.” In the nursing home, decisions were all made for him - such as when the television would be turned on, etc. The nursing home called “all the shots.” William said, “Now I’m the shot caller.”

Their adjustment to living in the community

ROBERT

- had to adjust to the fact that he “no longer had a call light.” He felt helpless at first. He also had to develop his own daily routine.

SUSAN

- told us that after being in the nursing home for so long, it was scary. It was a big change to not be around a lot of people anymore – everything was so quiet. Also she had become used to the routine of the nursing home and the regimentation. It took a while to establish her own schedule. She had to learn how to do things on her own again.

Their adjustment to living in the community

- Some individuals were leaving a facility after having become disabled for the first time in their lives or were going to be living on their own for the very first time.
- Had to adjust to a new life as well as a new environment.
- **BETSY** said the biggest adjustment was living on her own for the first time in her life.
  - It was an adjustment not having a car to go wherever she wanted, whenever she wanted and to have to learn how to use public transportation.
  - It was an adjustment having to depend on others so much.

Their recommendations for improving the transition process

- **A program or training to better prepare you to take care of yourself and to educate you on living without having someone there to help 24/7**. They said this is important because "everything is done for you in the nursing home.
  - "I didn't have to worry about paying for cable or grocery shopping in the nursing home."
  - "A lot of times I didn't know what to make or fix to eat. I only knew how to do things the way the nursing home did them."

Their recommendations for improving the transition process

- **Examples of topics to cover:**
  - Basic skills (e.g. menu planning, meal preparation)
  - Personal care (e.g. how to bathe by yourself)
  - Paying bills and managing your own money
  - “What you will have to deal with”

Their recommendations for improving the transition process

- **Training on hiring, training, managing caregivers.**
  - A number of people indicated that they didn't know how to go about finding and selecting their caregivers.
    - **KATE** said it was difficult for her to hire her caregivers. She said she got a pamphlet from IHSS about hiring/how to interview and a list of people to call, but it was hard for her to call strangers and figure out how to choose someone. She didn't know what questions to ask.
    - **TOM** said he had trouble getting workers and that a registry just for individuals transferring out of the nursing home would be helpful.

Their recommendations for improving the transition process

- **Detailed written information about the transition program. Information should include:**
  - What the transition coordinator will do
    - **KATE** was given a list of low income housing and thought that she had to find a place herself and then tell her transition coordinator. She really struggled to go see the apartments herself. She then realized that you can identify a possible apartment and then ask the transition coordinator to go with you to see it.
  - What is going to happen, each step of the process (e.g. a checklist)

Their recommendations for improving the transition process

- **Emotional support, if needed**
  - **KATE** felt the move was difficult emotionally. She had been in the nursing home for so long that it was hard to leave because she had many friends there.

Their recommendations for improving the transition process

- **Assistance that continues after the transition program support ends**
  - CCT stops after one year. People said they didn't know where to go for help after that time.

Our additional preliminary recommendations

- **Teach the consumer how to look for, interview and select caregivers by having the transition coordinator go through the process with the consumer.**
  - This gives them the experience while having someone to coach them through it.
- **Connect consumers who are transitioning to another person who has already transitioned. Create a sort of buddy system.**
  - This would help provide emotional support and encouragement particularly when they are feeling so alone just after leaving the nursing home.

Our additional preliminary recommendations

- **Give the individual an "onsite experience" to practice living on their own prior to the day of the move**
- **Allow caregivers to connect with the individual prior to leaving the nursing home.**
  - **WILLIAM's** caregivers came to the nursing home two days before the move and helped him pack up. He said that this was incredibly helpful because not only did this help with the move, it gave him a chance to get to know the workers and for them to meet his family.
- **Promote consistency among transition coordinators**

For more information …

- *Nursing Home Transitions in California*: http://www.theconsumervoice.org/sites/default/files/NHTransitionsinCA.pdf

- *Piecing Together Quality Care, No Matter Where*: http://www.theconsumervoice.org/piecing-together-quality-long-term-care

- Consumer resources on the Consumer Voice website: http://theconsumervoice.org/resident

Questions?

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The National Long-Term Care Ombudsman Resource Center

LONG-TERM CARE OMBUDSMEN: SUPPORTING THE CONSUMER

Amity Overall-Laib

Manager, Long-Term Care Ombudsman Program & Policy

What is NORC?

- Funded by the Administration on Aging (three year grant)
- Operated by the Consumer Voice in cooperation with the National Association of States United for Aging and Disabilities (NASUAD)
- Provides support, technical assistance and training to state and local long-term care ombudsman (LTCO) programs
  - Information, consultation and referral for LTCO and those that use LTCO services
  - Training and resources for state and local LTCO programs
  - Promote awareness of the role of LTCO
  - Works to improve LTCO skills, knowledge, and effectiveness in both program management and LTCO advocacy

What is a Long-Term Care Ombudsman?

- A Long-Term Care Ombudsman (LTCO) is a resident advocate.
- LTCO advocate for quality of care and quality of life of residents in long-term care.
- LTCO help residents benefit from relevant laws and regulations.

Functions of LTC Ombudsman Programs

- Resolve complaints on behalf of individuals
- Provide information, consultation, education to residents, families, and facility staff about resident interests
- Provide information and assistance to individuals (e.g. how to look for a LTC facility, LTC resources and options)
- Provide community education (e.g. presentations regarding LTC issues, awareness of the LTCO program)
- Support Resident and Family Councils
- Advocate for systemic changes to improve residents' care and quality of life

LTCO Network*

Who are they?

- 53 State LTCO Programs
- 1,110+ staff LTCO (state and regional)
- 8700+ certified volunteer ombudsmen

What do they do?

- Investigated **193,650** complaints
- Visited **25, 262** LTC facilities quarterly
- Attended **21,365** Resident Council meetings
- Conducted **5,049** facility in-services
- **309,423** instances of providing information to individuals

*Based on 2012 National Ombudsman Reporting System (NORS) data

Scope of Ombudsman Work

- LTC Facilities defined by Older Americans Act (OAA) as:
  - Nursing facilities
  - Board and care homes
  - Assisted living
  - Other similar adult care facilities

Role of the Ombudsman in Transitions

Keep the process focused on the resident's interests and priorities:

- Complaint investigation and resolution
- Support for the resident during the process
- Information about rights/options;
- Identify residents interested in transition; referral to appropriate agencies
- Being alert to issues that recur or are widespread

Coordination of services is not a typical ombudsman role

Ombudsman Involvement

- Sharing information about transitions and community based options
- Identifying residents who want to transition
- Assisting with connections to transition coordinators
- Advocacy:
  - Transition plan development
  - Transition plan implementation
  - Post transition advocacy

LTCO Systemic Advocacy

- Participate in workgroups, advisory groups, or other planning and monitoring activities at the state level
- Design of state plans, systems – responsive to resident interests
- Advocate for policies, laws, regulations – e.g.. eligibility for Medicaid, accessible housing options
- Advocacy/education with partners – Aging and Disability Resource Centers (ADRCs), providers, Medicaid Agency, discharge planners, etc.
- Diversion to other options
- Community/consumer education regarding rights, options

LTCO are Resident Focused

- What does the resident want? Resident participation in discharge/transition planning
- Resident empowerment
- Interests of the resident vs. the family; guardian/agent; facility
- Making the system work for the resident
- Protection of rights

New Options for Consumers

- Money Follows the Person (MFP)
  - Choices for individuals in where they receive services and support
- Minimum Data Set (MDS) 3.0 Section Q
  - All residents asked about transitioning out of the nursing home

Ombudsman Participation in MFP

Newly Expanded Services (some MFP states)

- Enhanced educational materials focused on Section Q
- Transition coordination (OH)
- Follow the resident into home care for one year (GA, DE)
- Follow up with the resident (MI – includes quality of life survey)

LTCO Role in Section Q Implementation

Expanded Services (some states)

- Enhanced educational materials/presentations to resident/family councils, facility staff, Aging Network regarding Section Q (Nebraska, North Carolina)

- Options counseling role in partnership with the Local Contact Agency (LCA) (Oklahoma)

Section Q Implementation Challenges

- Insufficient community resources to support transition and continued stay in the home care setting
- Delays in the process
- Challenges in discussing adequate community options with residents with dementia or diminished capacity
- Family/guardian/agent disagreement with resident choices
- Emotional stress of residents being asked if they'd like to transition

Section Q Successes

- Residents are returning to the community
- Improved collaboration and communication between nursing home staff and other agencies
- Nursing Homes have improved their communication with residents especially during care plans and explaining community options
- Residents have better understanding of their rights and community options

Federal Government Support for Ombudsman Involvement in Transition Work

"The Office of the State LTC Ombudsman is a stakeholder that should be included in the development and implementation of all MFP programs. They are a critical resource to provide information to the [State Medicaid Agency] on how the Section Q referral and follow-up process is functioning and to handle consumer complaints should they arise."

November 2010 Letter from Cindy Mann (CMS) and Kathy Greenlee (AoA)

LTCO Supporting Home Care Consumers

- 13 States have authorized expansion of LTCO services to home care consumers
  - AK, DC, ID, IN, ME, MN, OH, PA, RI, VT, VA, WI, WY

- MFP recipients – 2 states have expanded LTCO services to follow the person transitioning to their new setting for up to 1 year (GA, DE)

LTCO Supporting Home Care Consumers

- Most frequent complaints:
  - Staffing
    - Staff not showing up and no back up for care
    - Not enough staff to provide all the care needed (or not approved for enough care hours per day)
  - Financial Exploitation
  - Denial, reduction, termination of services

LTCO Supporting Home Care Consumers

- What Ombudsmen say:
  - Harder to build relationships since “not under one roof”
  - More time consuming to investigate because “not under one roof”
  - Difficult to get providers to work with/accept ombudsmen – new to work with
  - Need to be knowledgeable about more issues – e.g., food stamps, landlord/tenant, rental
  - Work feels reactive instead of proactive

LTCO Supporting Home Care Consumers

- Conflict of Interest:
  - Real & perceived
  - Multiple hats
  - Other agency programs/services

Get to Know…

- Long-Term Care Ombudsman Program (state and/or local)
- ADRCs
- Transition Coordinators
- State Local Contact Agency (LCA)
- State and local partners involved in transition programs and supports
- Nursing home social workers

Resources

- **NORC** (HCBS, MFP, MDS 3.0 Section Q)
  - www.ltcombudsman.org
- **Administration for Community Living- Home and Community Based LTC (Care Transitions)**
  - http://aoa.gov/AoARoot/AoA_Programs/Tools_Resources/Care_Transitions.aspx
- **Medicaid.gov Community Living Initiative** (MDS 3.0 Section Q resources, state Local Contact Agency for Section Q referrals contact list)
  - http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Community-Living/Community-Living-Initiative.html
- **Centers for Medicare and MedicaidServices (CMS)**
  - "Your Right to Get Information about Returning to the Community" brochure http://www.medicare.gov/publications/pubs/pdf/11477.pdf
  - Medicare Learning Network (discharge planning booklet for providers and checklist for consumers)
- **Aging and Disability Resource Center (ADRC) Technical Assistance Exchange (TAE) MFP Demonstration**
  - http://www.adrc-tae.acl.gov/tiki-index.php?page=MFPDemo

Questions?

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