Effective Advocacy in Long-Term Care Settings

A Team Approach

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The Facts

National Data

- By 2030, the number of Americans aged 65 and older will more than double to 71 million older Americans, comprising roughly 20 percent of the U.S. population.
- In some states, those over age 65 will equal roughly 25% of the population.
- Trends indicate that for persons >25, there is a 1 in 4 chance of at least one nursing home stay during their lifetime.
- 78.2 million/7918

New Mexico Data

- Fastest growth rate is of those over 85.
- More than 38,000 New Mexicans suffer from dementia related illnesses.
- More than 13,000 New Mexicans age 65 and older suffer from depression.
- More than 12,000 New Mexicans live in LTC facilities.
- By 2030, individuals over 65 will out number those under 18.

Aging Gracefully?

- Mission: The right service to the right person in the right setting

- Issues
  - Patient-hood vs. Person-hood
  - Surplus Safety vs. Dignity of Risk
  - Choice/Control and Independence

- Change the “Culture of Aging”
  - Presently - “Just Don’t Do It”
  - Long-term services – not just for elders
  - Shared Voice
What are the tools of Advocacy?

1. Be Informed
2. Be Prepared
3. Be Present
4. Be Creative
5. Be Heard
Be Informed

Quality of Care: Helpful Websites

Facility Quality
- www.medicare.gov *
  - Resource Locator – Nursing Home, Home Health, Hospital Compare sites
  - CMS Facility 5 star rating system

New Mexico & Federal Regulations
- http://www.health.state.nm.us/HFLC/HFLCregindex.html
  - Regulations Governing NM Health Care Facilities
- http://dhi.health.state.nm.us/elibrary/regulations.php
- http://dhi.health.state.nm.us/providersearch/index.php
  - Survey results, locate licensed residential care and nursing facilities

Rights, Advocacy and Quality Improvement
- www.theconsumervoice.org
  - Consumer Guides and Fact Sheets on Advocating for Good Care
  - National Ombudsman Locator
- http://assistedlivingconsumers.org
  - Guidebooks for Choosing a Facility

Medicare/Medicaid information

Request to see latest facility survey report!!
<table>
<thead>
<tr>
<th>Finding the right place: What does one look for?</th>
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<tr>
<td><strong>Environment</strong></td>
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<tr>
<td>• appearance &amp; cleanliness</td>
</tr>
<tr>
<td>• sounds, smells, temperature, etc</td>
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<td>• home-like? personal possessions?</td>
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<tr>
<td><strong>Staff</strong></td>
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<tr>
<td>• day/evening/weekend ratio of staff to residents</td>
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<tr>
<td>• Interaction: staff to resident, staff to staff, nametags worn?</td>
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<td>• response time to call lights, requests for assistance</td>
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<td>• training, availability of medical staff</td>
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<td><strong>Services/Policies</strong></td>
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<tr>
<td>• included and add-on costs</td>
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<tr>
<td>• for special needs (e.g. therapies, dementia care, etc)</td>
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<td>• discharge policies when care needs exceed facility’s scope</td>
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<td><strong>Activities</strong></td>
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<tr>
<td>• posted activity calendar, observation</td>
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<tr>
<td>• gender-appropriate, multigenerational?</td>
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<tr>
<td>• variety/indoor-outdoor</td>
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<td>• for bed or room-bound residents?</td>
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<tr>
<td><strong>Residents</strong></td>
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<tr>
<td>• appearance/grooming</td>
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<tr>
<td>• care planning/assessments</td>
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<tr>
<td>• engagement</td>
</tr>
<tr>
<td>• resident feedback</td>
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<tr>
<td><strong>Licensing</strong></td>
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<tr>
<td>• annual survey - 9-15 month window, complaint surveys – as needed</td>
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<td>• indicators of care important to you e.g. infection control, pain management, medication administration</td>
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<tr>
<td><strong>Meals</strong></td>
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<tr>
<td>• choice? appetizing? variety? accommodate special dietary needs? alternatives? snacks?</td>
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<tr>
<td>• assistance with feeding</td>
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<tr>
<td><strong>Other</strong></td>
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<tr>
<td>• safety: smoke detectors, sprinklers, handrails</td>
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<tr>
<td>• turnover rates – staff, administration</td>
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<td>• unannounced visits</td>
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Be Prepared: What Resources are available for Long-Term Care/Benefits/Legal Decisions?

Aging and Disability Resource Center
- 1-800-432-2080
- [http://www.nmaging.state.nm.us/Resource_Center.html](http://www.nmaging.state.nm.us/Resource_Center.html)
- [http://www.nmresourcedirectory.org/](http://www.nmresourcedirectory.org/)

Consumer and Elder Rights Division - Benefits Counseling Programs, SHIP (state health insurance program), Senior Medicare Patrol
- 1-800-432-2080

Ombudsman Program
- Santa Fe: 1-866-451-2901
- Albuquerque: 1-866-842-9230
- Las Cruces: 1-800-762-8690

Senior Citizen’s Law Office/Lawyer Referral for the Elderly Program
- 505-265-2300
- 1-800-876-6657
- [www.sclo.net](http://www.sclo.net)
- [www.nmbar.org](http://www.nmbar.org)
Protecting Vulnerable Adults in Long-Term Care Facilities

FACILITIES PROTECTIVE SERVICES CONTINUUM

Who: Caregivers  Ombudsman  APS  DOH/HFLC*  Law Enforcement

What: Direct Hands-on assistance  Resident advocacy  Complaint investigations  Annual & Complaint surveys  Prosecution Litigation
Choices/Wishes Investigations  Citations  Fines  Citations  Fines

*HFLC = Health Facilities Licensing and Certification
New Mexico’s 2003 Public Health Act states “The department (DOH) shall develop a health facilities protocol in conjunction to ensure the health, safety and rights of individuals in health facilities.

- Department of Health
- Adult Protective Services
- Ombudsman
- Human Services Department (Medicaid Fraud)
New Mexico
LONG-TERM CARE
OMBUDSMAN PROGRAM

Resident-Centered Advocacy Services

“To the world you may be one person, but to one person you may be the world”
~Anonymous
SCOPE OF THE OMBUDSMAN PROGRAM

• Federal & State Mandates
  – OAA
  – NM Long-Term Care Ombudsman Act

• Health Oversight Agency

• Authority to:
  • Conduct Investigations (overt, undercover, with “granny cams”)
  • Access Medical Records
  • Assess Civil Monetary Penalties

• Systemic Advocacy
  • Community Education & Outreach
  • Facility In-service training
  • Legislative Advocacy
How we are different...

- Not regulators
- Facility access anytime, for any reason
- Can enter unlicensed facilities
- Can make recommendations for change
- Can negotiate a family/facility crisis
- Can contest an inappropriate discharge
- Resident-centered vs. Systems-centered
What is the role of an Ombudsman?

“Carrier of the Message”

- Finds out the resident’s wishes/concerns
- Advocates on behalf of the resident

An Ombudsman investigates and resolves complaints and works towards empowering the resident

An Ombudsman is independent of the long-term care facility

Services are free and confidential
Rights of Residents

*Long-Term Care residents have special rights; they are in addition to the rights we all have as citizens of the U.S.*

- Fairness
- Freedom
- Choice
- Privacy

AND....

The *Right* to live in the least restrictive setting possible
Transition Advocacy Program: Background

- National trend toward Home and Community-Based Services
- In NM – Managed Medicaid in operation since 2008
- Ombudsman program began transition advocacy services to:
  - Protect a resident’s **right** to receive care in least restrictive setting possible
  - Promote communication and cooperation between all entities involved in discharge planning
  - Ensure that resident has a voice throughout the process
- Services are free. **Any** individual who wishes to transition to a less restrictive care setting, or return home, may request our services.
How the process works...

- Self-referral, referral through family or facility social services staff

- We meet with Resident to discuss:
  - His/her wish to return to the community
  - Our role in the transition*
  - Potential barriers/needs for successful transition *

- We discuss potential discharge with various entities
  - Type of transition to take place and technical assistance needed
  - Facility has ultimate responsibility to ensure a safe and appropriate discharge

- Post-discharge follow-up
  - Resident Permission
  - Up to 6 months (in-person, telephonically)

*Not every discharge will require our involvement
*We promise a voice, we do not promise a particular outcome
Be Present: How can individuals and their loved ones ensure good care?

- Visit, Visit, Visit, Visit, Visit, Visit!
  - Different days, different times
- Participate in care plan meetings, physician visits, discharge planning, home health assessments
- Become familiar with standards of care and Resident’s Rights
- Get to know the Ombudsman
Resolving Concerns/Complaints

Who can I call with concerns/complaints?

- Department of Health: 1-800-752-8649
- Adult Protective Services: 1-866-654-3219
- Ombudsman: 1-866-842-9230

Helpful Hints

- “Constructive Complaining”
  - identify which person can answer your questions
  - timing and approach
- What to Mention
  - who/what/where/when/what time?
  - one time vs. recurrent issues
- Request a care plan meeting
Be Creative:
How can one participate in a loved one’s care?

- Primary vs. Secondary Caregiver Roles
- Help caregivers know a loved one’s “story”
  - (interests, habits, beliefs, likes/dislikes)
- Create a feeling of home
- Volunteer in the Activities Program
- Bring civic/social/spiritual organization to the facility
Be Heard: How can one participate in civic action and systems advocacy?

- Resident or Family Councils
- Federal & State Legislative efforts
- Join the Aging Network
- Become a LTC Ombudsman and advocate for residents
For More Information:

New Mexico Long-Term Care Ombudsman Program

Santa Fe & Northeastern NM: 1-866-451-2901
Albuquerque & Northwestern NM: 1-866-842-9230
Las Cruces & Southern NM: 1-800-762-8690