

CONSUMER RIGHTS TO QUALITY OF LIFE & QUALITY OF CARE: AN INTRODUCTION TO LONG-TERM CARE OMBUDSMAN SERVICES

Kim Marheine, Kathi Miller, Sarah Oneil

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Living a Self-Determined Life

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STATE OF WISCONSIN BOARD ON AGING AND LONG TERM CARE

Long-Term Care Ombudsman Program/Helpline
1-800-815-0015

Medigap Helpline
1-800-242-1060

Part D Helpline
1-855-677-2783

Medigap Counselors

- Medicare Supplemental & Advantage Plans
- Medicare Supplement Policies (Medigap)
- Long Term Care Insurance Options
- Medicare Part D benefits & enrollment
- COBRA & Continuation Options
- SeniorCare Drug Assistance Program
- WI Medical Assistance
- Military/Veteran Health Benefits

Volunteer Ombudsman Program

- VO's receive criminal background checks, thorough orientation and continuing education
- VO's are resident spokespersons, always acting only with consent
- VO's are assigned to specific facilities, visiting regularly, usually weekly
- VO's communicate concerns in need of follow-up to assigned Regional Ombudsman
- VO's are alert to both challenges & successes, & can be a source of stability in homes where there are many changes in staff, leadership, policy, performance

Long Term Care Ombudsman Program

A Voice for Consumers of
Long-Term Care Services

Om-budz-man

The word Ombudsman is Scandinavian.

In this country the word has come to mean an advocate or helper.

An Ombudsman protects and promotes the rights of long-term care consumers.

Working with clients, providers and families, ombudsmen work to ensure the client's voice is heard above all others. The program is authorized by both state and federal law.

Ombudsman Program Authorization

- Congressional authorization through the Older Americans Act, providing for unrestricted access to Ombudsman program services
- Additionally, provides unrestricted access to Ombudsman by clients, and unrestricted access to clients by Ombudsmen “at any time and without notice.”

Source: 45 CFR 1324 & §16.009(4)(a), Wis. Stats.

Ombudsman Program Authorization

- Client identity & concerns held confidential, unless permission is granted for disclosure
- Providers must assure “private & unrestricted communication”
- Independent advocate for clients in resolving concerns relating to long-term services and supports, providers, individuals, regulators or other parties

Role of the Ombudsman

- Focus on the rights of long term care consumers, to assure quality of life and quality of care. In WI, persons over age 60, residing in licensed LTC settings, recipients of Family Care, PACE, Partnership or IRIS services
- Investigate complaints of rights violations, inadequate care and services, denial of benefits, issues with access to services and supports
- Challenge resolution, striving toward positive outcomes for client – always and only the client

Responsibilities of the Ombudsman

- Discuss care options, refer to ADRC for options counseling
- Resolve challenges
- Consultation services to providers, MCOs, ICAs/FEAs, individuals
- Provider and Community Education
- Resident/Tenant & Family Councils
- Systems Advocacy (local, state and federal)

Rights...

- Are guaranteed by state and federal laws
- Direct that everyone – staff, families, volunteers, visitors – are required to respect, protect and promote an individual's rights
- Guarantee that every person has the right to exercise all of her or his rights free from interference, coercion, discrimination or retaliation.

The foundation of Clients Rights states that each person has the right to be treated as an individual, with courtesy, respect and dignity at all times and under all circumstances.

Most Common Complaints in LTC

- Right to exercise individual liberties and to lead a dignified existence (*right to exercise choice*)
- Rights regarding health care and lifestyle risks and benefits, including right to self-determination (*care and treatment*)
- Rights related to decision-makers who over-restrict; persons who are not decision-makers who self-appoint and then restrict client choice or care
- Rights to privacy in medical and personal care, in correspondence and visits, in treatment of personal records and belongings

Most Common Complaints in LTC

- Access to client-specified services and supports, such as ramps, chair lifts, motorized chairs and scooters, home modifications
- Access to particular types of services such as acupressure, warm water therapy, purchase and training of a service animal
- Desire to receive care at home vs. in a LTC setting, when care involves specialized needs such as tracheotomy and tube feeding care, dialysis
- Rights related to respect for end-of-life decisions made by the client when in conflict for desires of family or others

Root Causes of Rights Violations

- Systemic
 - Paternalistic view of society toward aging and older adults
 - Stigma
 - Medical model of care(giving) vs. person-directed or person-centered
- Individual
 - Education
 - Life experience
 - Family dynamics

Brief BOALTC Data 2016 - 2017

- 1285 total new cases opened (1008 last yr); >12,000 individual case contacts toward resolution
- >35,000 total requests for consultation (~33,500 last year)
- 4342 consultations to facility staff
- 238 education and outreach programs to community groups, networks
- ~110,000 long term care consumers over age 60; 20 long term care ombudsmen (one Veterans' Ombudsman, one Managed Care Ombudsman, 2 IRIS Ombudsmen), one Relocation Ombudsman, one Intake Specialist, one Lead Ombudsman

About Self-Determination

- Self-determination and substitute decision-making should not be either/or, but should work in collaboration to preserve and respect an individual's autonomy.
- All persons have fundamental rights.
- Substitute decision-makers must be aware of the rights and preferences of the individual, and must know the parameters of their roles.

POA's and Guardians

- Health Care POA's make health care decisions only, and agree to serve according to the desires of the principal (individual).
- Guardians make decisions in the best interest of the ward (individual), but must still also consider the ward's personal preferences and desires.
- A guardian must promote the greatest possible integration of the individual into her or his community.

Rights & Surrogate Decision-Makers

- Agents clearly have a legal obligation to do what the principal wants
- Guardians are charged with making “best interest” decisions, but the statutes specifically direct the guardian to consider what the ward wants
- Absent a Guardianship or Activated Health Care Power of Attorney, in Wisconsin a person’s family has no authority to dictate care and treatment

Balancing Rights & Protections

- Recognize and respect life history, life choices, expectations for the present and the future
- Create resolution by emphasis on strengths vs. threats of losses
- Encourage change by consensus, mediation, conciliation vs. by order
- Success is best insured by building relationships and trust vs. by mandates and rules

Negotiating Risk

- Premise that persons have a right to choose and refuse, to take risks, and to live in accordance with other values besides optimal health and safety.
- Some of the toughest choices are those in which the individual would decide to choose freedom over safety. Appropriately negotiated risk could accomplish both.

More Points to Consider

- **Younger individuals:** risk may be assessed and negotiated on the basis of current skills and potential to learn new skills, goals for future, often leading to higher degrees of acceptable risk with good wrap-around of supports
- **Older individuals:** risk may be assessed and negotiated on the basis of history and deficits, often leading to denial of request for risk, and at most extreme, imposition of guardianship in order to “protect”

Older Adults and Self-Direction

- Older adults in institutional care seem to defer most decisions, and sometimes even expressions of self-determination relative to quality of life and end-of-life care, to an adult child, trusted friend, facility staff.
- Some that do attempt to actively self-direct are sometimes labeled as “challenging,” “unrealistic,” or “lacking insight,” particularly in facilities or within MCO/health care structures that have a paternalistic view of their roles.

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Resources

- **Board on Aging & Long Term Care**
Advocacy agency for LTC consumers age 60 and older
1-800-815-0015/longtermcare.state.wi.us
- **Disability Rights Wisconsin**
Protection & Advocacy agency for persons with disabilities
1-800-928-8778/disabilityrightswisconsin.org
- **Division of Quality Assurance (DQA)**
Licensing agency for WI LTC facilities
608-266-8481
- **Nursing Home Compare**
Website to compare NH standards, Statements of Deficiency
www.medicare.gov/NHCompare
- **Assisted Living Comparisons**
<http://www.dhs.wisconsin.gov/bqaconsumer/>
- **Wisconsin Guardianship Support Center**
1-855-409-9410/guardian@gwaar.org