

Final Report of Consumer Rights Subcommittee,

Elder and Vulnerable Adult Abuse Prevention Working Group

Chair: Cheryl Hennen, State Ombudsman for Long-Term Care

About this Report

Since adjournment of the 2018 legislative session, stakeholders considered how to build on the momentum created for reform in the area of abuse and neglect of vulnerable adults. Commissioner Jan Malcolm noted important agreement among stakeholders that broader changes were needed in policy and practice in our statutory frameworks, in regulatory agencies, in care settings, and in communities across the state. Therefore, Commissioner Malcolm asked work groups to form on topics including Consumer Rights.

The Consumer Rights Subcommittee was chaired by Cheryl Hennen, State Ombudsman for Long-Term Care, and met on four occasions in 2018: September 14, October 3, November 7, and November 27. Meeting minutes and agendas were sent via e-mail and available on MDH dedicated website. In addition, comment/input was solicited from each committee member via e-mail.

The Subcommittee had participation from a wide variety of stakeholders: governmental agencies, legislative staff, providers, legal services, family members of vulnerable adults, nonprofits, the Office of Ombudsman for Long-Term Care, and others.

The Subcommittee agreed on three primary areas of consumer rights needing focus: (1) strengthening rights, (2) enforcement of rights, and (3) education about rights. These focuses served as the locus of Subcommittee discussions.

The Subcommittee identified shared values, including:

- Ensuring the voice of the person/resident is heard
- Equitable solutions to boost the consumer voice
- Transparency
- Honesty
- Kindness
- Protecting Rights
- Presence and equality of all individuals being honored
- Autonomy
- Collaboration and listening to different perspectives and experiences
- Quality of services and quality of life
- Education
- Listening to and hearing people
- Dignity, respect, and choice
- The right to live in peace and independently

- Safety; continuity of care
- Informed choice
- Person-centeredness and ensuring that the person who is impacted is the one who is making the decisions and driving what occurs.

The Subcommittee discussed numerous issues related to consumer rights, which are discussed below by topic. Areas of agreement are listed below, as well as other points raised by Subcommittee members related to each topic. For points not listed under “areas of agreement,” these are either areas where the Subcommittee was not able to finalize discussions regarding agreement or where there was disagreement. More specifics on Subcommittee discussions can be found in the Subcommittee’s meeting minutes.

Subcommittee Discussions by Topic

Retaliation in Assisted Living and Home Care Bill of Rights

Summary of the issue: There is strong agreement that it is important for assisted living residents to be protected from retaliation. For a right to be meaningful, a person must be free to exercise it without retaliation. There are currently some protections against retaliation in law, but there is no clear protection from retaliation with enforcement through the Home Care Bill of Rights.

There was agreement on the need for better regulatory enforcement of retaliation in the Bill of Rights. Multiple participants raised the importance of clarifying and strengthening the definition of retaliation in the Bill of Rights. Some participants stated that private enforcement is needed to ensure protection from retaliation.

- Areas of agreement:
 - We need to identify and define retaliation and enforce through regulation during health department surveys.
 - Enforcement of the Home Care Bill of Rights needs to improve.
 - Retaliation is unacceptable and not to be tolerated within any long-term care environment/service.
- Considerations:
 - Multiple participants felt that there were inadequate protections against retaliation in assisted living.
 - Some participants stressed the importance of strengthening the Health Care Bill of Rights (144.651 HEALTH CARE BILL OF RIGHTS) by defining retaliation:

- 1) Unlike definitions in other statutes, there is no real definition of what retaliation means in the Home Care BOR (BOR distributed to recipients of Home Care service in Assisted Living). Retaliation needs to be clearly defined in order to be adequately enforced (e.g. refer to Ombudsman statute; includes a rebuttable presumption). How is non-compliance to be quantified, what evidence is used to substantiate non-compliance, etc.?
 - 2) Review of related statutes: Minn. Stat. § 626.557 this statute may not always apply to cases of retaliation in assisted living because investigations do not always rise to the level of maltreatment.
- The Subcommittee reviewed applicable statutes currently in law related to retaliation applicable in assisted living.
 - Minn. Stat. § 626.557 (VAA reports; only private right of action in these statutes); Minn. Stat. § 504B.285 (defense to eviction), Minn. Stat. § 256.9742 (misdemeanor, ombudsman statute). These statutes each have a burden-shifting framework for retaliation.
- Minn. Stat. § 144A.44, Home Care Bill of Rights, speaks to the services side of assisted living and retaliation in that context.
 - It does not have a burden-shifting framework or a definition of retaliation.
- The subcommittee did not reach consensus on private right of action.

Enforcement and Fines in Assisted Living and Other Settings

Summary of the issue: There is strong agreement that enforcement of rights is critical to ensure that rights are respected. Gaps exist in enforcement of statutes applicable to assisted living. Subcommittee members agreed there must be increased enforcement of the Home Care Bill of Rights from the Minnesota Department of Health, including increased penalties for some violations of home care statutes in assisted living settings. Multiple participants also stressed the need for other enforcement protections and increased criminal penalties for right violations.

- Areas of agreement:
 - Consistent enforcement of the home care statutes in assisted living, including but not limited to the Home Care Bill of Rights.
 - If additional language is needed to make it clear that MDH should enforce the Home Care Bill of Rights, such language should be enacted.
 - MDH should, at minimum, have adequate staffing resources to survey all providers within applicable statutory requirements regarding surveys of assisted living settings.

- MDH is not currently complying with requirement to survey assisted living settings every three years, and some assisted living settings are not surveyed at all due to lack of proper staffing resources.
 - There may be a need for increased penalties for some violations of home care statutes in assisted living settings.
 - There should be additional definition of how the money for fines collected by MDH in assisted living is used.
- Considerations discussed:
 - Some committee members support court actions for private claims after the death of residents.
 - Some committee members did not agree that there should be private rights of action or court actions for private claims after the death of residents, stating that the enforcement should be regulatory.
 - The relationship between rights and duties is important when looking at statutory language especially related to Home Care Bill of Rights (HC BOR). The HC BOR does not include language clearly defining a duty or clear responsibility of the provider. In comparison Federal BOR for nursing home residents requires nursing homes to “promote and protect the rights of each resident” and stresses individual dignity and self-determination.
 - Enforcement needs to fit the violation and based on specific rights
 - The need for increased fines for violations in nursing homes
 - There should be increased criminal penalties for violations of consumer rights in long-term care
 - Protection of rights should not only be focused on issuing fines but also how to optimally guarantee the protection of every resident’s rights.
 - Honoring resident rights prevents abuse.
 - Fines collected as a result of violations to the home care statutes should be held in a special fund to be used for quality improvement and training activities within home care.

OOLTC Funding and Education

Summary of the issue: There is strong agreement that the Office of Ombudsman for Long-Term Care needs additional funding. The Ombudsman Office will request 10 additional staff next legislative session; 9 additional regional ombudsmen and one supervisor. The Ombudsman’s Office advocates for consumers, provides information, focus on person-centered care, prevention of abuse, and other educational efforts, including consultations with individuals and providers. Additional staff statewide will fulfill the mandate of a presence for residents to ensure their voice is heard, resolve matters at the lowest level whenever possible, communicate systemic concerns, and recommend changes to laws, rules, and policy to improve quality of life/care.

The Office staffing ratio has about 9,000 beds to every 1 regional ombudsman, which includes nursing home and assisted living settings. There are also large geographic regions and significant travel time (as much as an average of 80 hours/month) for many ombudsmen.

Additionally, there is agreement that consumer rights education is needed more broadly to include providers of service, family members, and other community members. People are empowered by education. Subcommittee participants shared ideas for improved education such as mandatory periodic reminders of rights and education for assisted living consumers at times other than admission or other crisis points.

- Areas of agreement:
 - There should be increased funding to the Office of Ombudsman for Long-Term Care.
 - There should be increased education of consumers, family members, and staff about consumer rights in long-term care.
 - People are empowered by education.
- Considerations:
 - Requirements for mandatory periodic reminders of rights and education at times other than admission or other crisis points
 - Distributing the Bill of Rights to residents when they have a complaint or on an annual basis
 - The 2 contract system (housing and services) may create barriers to knowledge of rights

Lease and Service Terminations

Summary of the issue: Aging in place where possible is a priority that has stated throughout Subcommittee discussions, including in the Assisted Licensure Subcommittee. Many Consumer Rights Subcommittee participants have identified additional protections for lease and service terminations as a top priority. Due to time limitations, there was limited opportunity to discuss this issue in the Consumer Rights Subcommittee. There was agreement, however, that this topic should be addressed by the Assisted Living Licensure Subcommittee.

- Areas of agreement:
 - There is room for consensus about improved, reasonable expectations and processes for lease and service terminations in assisted living settings.
 - This topic should be addressed in the recommendations of the assisted living licensure workgroup.

- Considerations:
 - Need for hearing and discharge processes in assisted living service and housing terminations.
 - Need for limited grounds for lease/service terminations. Currently a home care service provider may terminate services for unlimited inconsistent reasons which places the individual receiving services at risk to be without services and arbitrary discharge.
 - Need for at least 30 days' notice for lease/service terminations in most instances
 - Need for documentation of actions taken to minimize need for termination of service prior to discharge.
- There are problems with deceptive marketing practices that promise care not followed, e.g. assistance with eating, 2-person lifts, etc., that can lead to termination notices when residents need such services and the services offered in marketing materials/promises are not fulfilled

Resident Feedback and Engagement in Assisted Living, including Resident/Family Councils

Summary of the issue: There is strong agreement that there needs to be a constructive feedback loop between assisted living staff, residents and families. Quality of life, respect for rights, and quality of care improve when consumers feel empowered and their voices are heard. Resident and family councils, along with other best practices, can help to promote consumer rights.

- Areas of agreement:
 - There needs to be a constructive feedback loop between assisted living staff, residents and families.
 - Residents should be encouraged to have a voice and be able to organize.
 - Define best practices when determining what resident and family engagement should look like in assisted living.
 - Residents should have an (ability or freedom) to organize and participate in resident groups in the setting.
 - An assisted living setting must provide a resident or family group, if one exists, with a space for meetings where one is available.

- Considerations :
 - Explore all ways to promote a constructive feedback loop between residents and staff other than Resident or Family Councils. Include best practices from assisted living providers with established procedures already in place documented positive results.
 - Resident and Family Councils are an important mechanism for raising the consumer voice and should be encouraged.
 - Resident or Family Councils have the potential to “streamline” concerns to the administration or to make it clear that more than one person has a particular issue.
 - Right/ability to have Resident or Family Councils may help resolve the fear of retaliation for expressing concerns and/or organizing a Council.
 - Some residents may have limited ability to inform other residents about Council meetings without support. Peer to peer support is an option to be considered.
 - The assisted living setting itself may create space barriers because some people reside in private apartments.
 - The Subcommittee discussed the nursing home regulation 42 C.F.R. § 483.10 and which parts might be applicable, if at all, to assisted living. Some disagreement on whether all language in this regulation should exist in assisted living because distinction is necessary between nursing homes and assisted living.

Disclosures

Summary of the issue: There is strong agreement that consumers deserve informed choice when deciding whether to move into an assisted living setting. Moves can be very difficult for people, recipients of service often spend down significant resources in an assisted living setting relying on promises that were made based on the information given through marketing materials and at admission. Information at admission is substantial and may be difficult to navigate especially given the situation is usually at the point of crisis and emotionally charged. Therefore, it is important that the services provided, availability of home and community-based waivers, and other important decisional factors are transparent to consumers. This is also an issue that has been discussed in the Assisted Living Licensure Subcommittee. Due to time limitations, there was not the opportunity to discuss in detail the issue of informed choice and disclosures in the Consumer Rights Subcommittee, important to note this was an issue raised by participants throughout meetings.

- Areas of agreement:
 - There was not enough detailed discussion on this topic to reach areas of agreement.

- Considerations:
 - Need for improved disclosures by assisted living settings regarding admissions criteria, services offered, and the potential reasons that a resident might need to move.
 - Need for increased protections to ensure that promises of care to be provided and promises related to acceptance of home and community-based waivers are kept, so that people are not discharged arbitrarily.
 - There are currently protections related to disclosures in law.

Examples of Things that are Working Well in Current System

- There are HWS/AL where people are having good experiences and providers of service are doing well.
 - How do we learn from them?
- Positive collaboration with stakeholders
- Increased awareness of rights/problems
- Good staff levels and training leading to good outcomes.
- People experience a higher quality of life when the culture of the environment supports person centered practices, positive attitudes, and administrators and staff are well educated/trained.
- Programs, agencies, and resources are in place which can be built on including ombudsmen, quality improvement agencies, protective agencies, and state department/ local agency/provider group collaborative' s .

Other Topics Raised in Subcommittee Meetings

- Below are some additional topics that were raised by Subcommittee participants. Due to time constraints consensus was not accomplished however each topic is noteworthy of future discussion and resolution:
 - Consolidating the Bill of Rights
 - Adding rights to Bill of Rights
 - Need for consistent language across statutes and plain language, including in Bill of Rights
 - Definition of consumer
 - Consumer fraud and deceptive marketing
 - Transparency in terms of a person's right to information about themselves in a maltreatment investigation.
 - Residents and families need more information when maltreatment reports are filed.
 - Staff shortages
 - Electronic monitoring to deter abuse and details on how to determine conflicts/who is the consumer – *electronic monitoring group is working on this issue*
 - Continuing the collaborative work of MDH workgroups

- Home and Community-Based Waivers (e.g. Elderly Waiver) caps and funding
- Recognize consumer rights cross over each subcommittee, each subcommittee should duly note applicable rights to topic or recommend additional rights needed.

Feedback from All Group Polling

- In an all-group meeting of the working groups, there were polls that took place on some of the topics addressed by the Consumer Rights Subcommittee.
- There was fairly strong agreement in the all-group meeting on the topics of:
 - Resident Council development in assisted living,
 - Funding for Office of Ombudsman for Long-Term Care
 - An improved process for lease and service termination in assisted living
 - Improved protections against retaliation in assisted living, and
 - Improved disclosures to consumers when choosing among assisted living settings.
- Details on exact polling results may be found in the polling document listed on the MDH working group website.