



# **Elder and Vulnerable Adult Abuse Prevention Working Groups**

SUMMARY REPORT

01/24/19

## **Elder and Vulnerable Adult Abuse Prevention Working Groups**

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## Executive Summary

Since adjournment of the 2018 legislative session, the Minnesota Department of Health (MDH) and many other stakeholders have worked to build on the momentum created for reform in the area of abuse and neglect of vulnerable adults. MDH has continued to make operational improvements in the MDH Office of Health Facility Complaints (OHFC) and the Health Regulation Division (HRD) in which OHFC resides, and is committed to continuing that work with the input of stakeholders including the legislature, consumers and families, providers, researchers and advocacy organizations. Beyond improving the enforcement of current regulations, there is important agreement among stakeholders that broader changes are needed in our statutory frameworks and in the policies and practices of regulatory agencies, long-term care settings, and communities across the state.

This document provides a summary of six informal working groups that came together at the invitation of the Commissioner of Health in the fall of 2018. The Elder and Vulnerable Adult Abuse Prevention Working Groups focused on the following areas: Licensure Approaches for Assisted Living Facilities; Certification of Dementia Care Units; Electronic Monitoring in Care Facilities; Consumer Rights; An Assisted Living Report Card; and Improving Quality and Safety in Long-Term Care Settings. The individual reports highlight areas of both consensus and disagreement among work group participants.

It is important to note that these informal work groups were not established by either the Legislature or the Governor, and had no dedicated funding or staffing. Rather, these reports were generated through an extraordinary commitment of volunteer time by members of the community and extra work beyond the regular duties of agency staff from MDH, DHS, and the Ombudsman for Long Term Care. Particular thanks go to those who agreed to lead each of the work groups. Furthermore, these reports do not reflect the official position of any organization. However, participants including the state agencies say that this collective work will inform the development and evaluation of policy recommendations as they engage in the 2019 session of the Legislature and beyond.

### **Assisted Living Licensure – convened by Jan Malcolm, Minnesota Department of Health**

This work group identified a number of principles, values, and design criteria to guide future policy development in this arena. Its discussions largely built off the Governor Dayton-appointed Consumer Work Group's 2018 legislative proposal and ideas from the Long Term Care Imperative.

While acknowledging that important details will be debated in the 2019 Session, the work group generally agreed with a new approach to increase regulatory standards, including these underlying concepts:

- In contrast to the current fragmented system with components of applicable regulations found in multiple statutes, everything related to assisted living should be placed into one chapter of law and enforcement streams should be clarified and simplified.
- Any level of services beyond housing for elders and vulnerable adults should require some level of regulation, beyond simply registration.
- The level of regulation should be appropriate to the mix of services offered, the level of need and complexity of the people being served, and the degree of consumer control over their choices in a setting.
- There should be more clarity and consistency in facilities' marketing materials, and more required disclosures before admission.
- Consumers should retain the ability to grow and age in place where possible, which includes the ability to bring in added services to their place of residence within reasonable limits.
- Providers should retain the ability to tailor what they offer, within limits.

MDH is currently preparing draft legislative language for review by the Administration, legislature, and stakeholders.

#### **Dementia Care Certification – convened by Beth McMullen, Alzheimer's Association Minnesota-North Dakota**

This work group focused on the idea that people living with dementia should not be required to live in dementia care settings and—because people with dementia live in all settings—determining which settings should meet minimum dementia training requirements. There is agreement that there should be additional certification or licensure for dementia care settings, such as standards and consumer disclosures, and also that dementia care standards in Assisted Living should take the same general approach—and not conflict with—nursing home standards. Recommendations were developed on staff training requirements, required disclosures, staffing patterns, physical environments, activity programming and behavior support plans, and medical management.

#### **Electronic Monitoring – convened by Amanda Vickstrom, Minnesota Elder Justice Center**

This work group was able to build off a 2017 legislative report, 2018 legislative proposals, as well as examples from other states. This report identifies areas of agreement and disagreement—including suggested legislative language—on several topic areas: definition of monitoring device, definition of resident representative, consent scenarios—including notice to others and withdrawal, resident rights and protections, facility liability, dissemination of data, obstruction of device, notice to visitors, and costs.

**Consumer Rights – convened by Cheryl Hennen, State Ombudsman for Long-Term Care**

This work group identified three themes: better educate consumers about their rights, better enforce those rights, and strengthen rights in key areas. This work group would also like to highlight the importance of the Office of Ombudsman for Long-Term Care and supports adding capacity to the office statewide. There is also agreement about improving protection from retaliation and encouraging or requiring resident and family councils.

**Assisted Living Report Card – convened by Kari Benson, Minnesota Board on Aging, Department of Human Services**

DHS is working to create an Assisted Living Report Card following a similar process used to create the Nursing Home Report Card. The work group agreed that a report card is needed and should be pursued as part of a multi-pronged effort to encourage and reward quality in long-term services and supports. Through a contract with the University of Minnesota, quality domains will be developed, existing and proposed measures will be organized and relevant data sources and data gaps will be identified. The work group urges that the experience of Assisted Living residents be captured via a statewide survey. DHS will refine cost estimates and timeline for such a survey.

**Improving Quality and Safety in Long-Term Care Settings – convened by Marie Dotseth, Minnesota Department of Health**

This work group plans to continue to meet to develop a work plan including projects for collective action not requiring legislation. There is agreement on shared values for a quality and safety improvement system that should:

- Be person-centered
- Be fair/just and promote accountability
- Be a learning system
- Optimize resident choices and safety concurrently
- Have a consistent regulatory approach across settings
- Work toward optimal standards of care and not just minimum standards

**Common Perspectives**

All work groups acknowledged the overarching challenge of the long-term care workforce shortage and urge more coordinated and concerted actions to develop and implement a strategy.

There was also agreement that this process has been very valuable to understand these issues from various stakeholder perspectives and building trust among parties. We intend for this collaborative spirit to continue. We hope that these work group products may be useful to executive branch agencies, legislators, and stakeholder groups.

## Office of Health Facility Complaints (OHFC) Operational Improvements Update

All Minnesotans deserve high quality and respectful care, and citizens in need of long-term care services in nursing homes and other adult residential care facilities have rights under federal and state law to quality care and quality of life. Over a third of Minnesotans older than 85 are under the care of a health facility or a home care provider. This qualifies them as a vulnerable adult as defined by Minnesota Vulnerable Adults Act. Currently there are 36,000 people living in 2,600 long-term care facilities and 90,000 people receiving home-based care. In 2018, OHFC received more than 22,509 allegation reports—an average of over 430 each week.

Over the past year, MDH has worked diligently with the help of DHS to address serious backlogs and quality gaps in receiving and responding to quality and service complaints. Rebuilding trust with victims, families, and the people of Minnesota has been and will continue to be a top priority.

On January 1, 2018, the OHFC backlog was at 2,321 unaddressed reports, and 826 open cases were awaiting onsite investigation. On March 1, 2018 the Office of the Legislative Auditor (OLA) issued a report which detailed failures and diagnosed causes including: delays in investigations, missed statutory timelines, lack of communication to families and providers, antiquated paper-based processes, and staffing, management, and morale concerns.

Governor Dayton asked MDH and the Department of Human Services (DHS) to collaborate on developing and implementing a rigorous plan to improve processes within OHFC in order to shorten the timeframe to respond to complaints and complete investigations of alleged maltreatment. As a result, the triage backlog was cleared on February 28, 2018 and the investigation backlog was cleared on August 8, 2018.

Of the 22,509 complaints in 2018, almost 1400 were assigned after a desk review for on-site investigation and about 780 investigations were completed. Of these, about 236 were substantiated (meaning a preponderance of evidence supported the claim), 127 were inconclusive (evidence was mixed), and 416 were not substantiated (a preponderance of the evidence did not support the claim). The 30% substantiated cases reflects a significant increase from the OLA reported findings of 16-19% substantiated cases from 2012-2016.

OHFC has developed an interim electronic document management system, but does not yet have a robust case management system. OHFC has also improved workflows and management practices, but these need to be hard-wired and continuously improved. OHFC has also worked to improve communication with those filing reports-- those receiving services and their families, as well as providers who self-report as required by law.

Going forward, MDH will continue to document and improve complaint investigation procedures and standardize workflows. We have begun to do a better job of involving staff at



all levels, especially the front line staff, in these improvement efforts. This is key to improving the work environment and increasing engagement and morale.

While ongoing work to meet the OLA recommendations continues, some efforts will require additional legislation and funding. MDH is also expanding our improvement efforts to the rest of our health facility regulation functions more broadly, and is continuing to explore ways to collaborate with DHS.

Finally, MDH is starting a major shift in the way we use data for improvement. A first effort is the OHFC dashboard, which is posted weekly on the MDH website. Beyond the report card (which is an important public accountability tool), MDH is working closely with MN.IT to develop new reports that can be run regularly to analyze data for management and improvement within the Health Regulation Division, and also for aggregated and de-identified data to be proactively shared with the public and providers. An important part of the MDH mission is to provide education and data to providers and the public to prevent maltreatment and to improve the health of vulnerable adults overall.

All of the data flowing through the regulatory system should be used for prevention and quality improvement, not only the minority of allegation reports that are found by a preponderance of the evidence to meet the federal and state definitions of maltreatment, abuse, neglect, and financial exploitation.

## Assisted Living Licensure

This work group began with discussion of shared understandings of the environment, including significant time spent on the history and evolution of Minnesota's regulatory approach to long term care. (See meeting notes and materials on the [website](#).) From there we articulated some key values we wanted to hold in our discussions, and that we think should inform future policy. We also felt it was important to specify both the problems we are trying to solve and the positive attributes of Minnesota's approach that we think are important to preserve.

## Shared Understandings

- All of us have the same reasons for engaging in this work: to improve health, safety and quality of life for elderly and vulnerable adults in Minnesota.
- We will honor the experiences and emotions of those who have suffered harm.
- Consumers consistently express a preference to remain in their own homes and communities.
- People have very different levels of need and complexity, and care needs can escalate very quickly.
- The needs of people being served today are quite different than what was envisioned when the conceptual model for assisted living was envisioned years ago.
- Minnesota has intentionally built a choice-oriented, market-based system, but we recognize that the marketplace is confusing for consumers and families now.
- Consumer protections and standards of care are only as good as their enforcement.
- Preservation of housing is important; we already face critical shortages.
- Workforce shortages exist now and will likely worsen.

## Values/Goals

- We seek to improve quality of life for all.
- We respect the rights, dignity and right to choice of elders and vulnerable adults.
- We will strive to balance personal rights, autonomy, choice and privacy with safety and health protection for vulnerable adults.
- We will value person-centered solutions over those that are primarily institution-centered.
- It is our goal to fill gaps in regulation to increase quality and safety, but it is not our goal to drive more people into institutions.
- At the same time, there is a need and a goal to maintain high quality nursing homes in the care continuum; this capacity must be maintained.
- Care settings need to be and remain accessible to low income populations. Any new regulatory system must allow sustained access to Home and Community Based Services Medicaid funding; access should be improved for those on Elderly Waiver.
- Whatever we do as a state we need to be able to pay for.

## Preserve and Build on what is Working Well

- Honoring consumer preferences, self-determination, and choice.

- Promoting compliance with the Americans With Disabilities Act, the Older Americans Act, the Fair Housing Act, and the state’s Olmstead Plan.
- Support for aging in place (for elders) and growing in place (for people with disabilities) as much as possible.
- Providing a continuum of supports that are accessible as needs increase.
- The state’s community based services programs, including compliance with the Medicaid requirements for home and community based services settings.
- Striving toward the goals and strategies in the state’s Olmstead plan: providing a full range of options and supporting people to live in the community to the fullest extent possible.

## Address Core Problems

While different issues were more and less significant from the perspective of different stakeholders, the work group generally came to agree on a number of core problems, including:

- Significant complexity and gaps in the current fragmented regulatory scheme
- Confusion for consumers and family members
- Insufficient protections for safety of vulnerable people
- Unclear and insufficient accountability for owners, operators and providers
- Inconsistent and insufficient enforcement by regulators

See the document [Additional Stakeholder Perspectives on Core Problems](#) on the working groups’ web page for greater detail.

## Recommendations for a New Regulatory Framework

- Convert the current Housing with Services Registration into a multi-level licensure approach
  - Level One would be Housing with Supportive Services only; including a standard definition of the services to be developed. (or a more descriptive term to capture non health-care)
  - Level Two would be Assisted Living Basic, offering health care services defined as basic in the home care licensure law.
  - Level Three would be Assisted Living Comprehensive, offering health care services defined as comprehensive in the home care licensure law.
  - Level Four (or certification in addition to Assisted Living licensure) would be for dementia and memory care services or units.
  - All providers who provide services currently outlined in section 144G.03, subd. 1 (title protection) will fall under assisted living licensure.

There were a range of opinions about the value and trade-offs of having fewer, or more, pre-defined levels of service to trigger different regulatory requirements. More levels could create more choice, but also more complexity.

## Specifications in the law would include

- Physical plant requirements
  - Both minimums (e.g., sprinklers) and criteria for new construction (e.g., accessibility needs)
- Specific criteria for client evaluation and admission procedures, and documentation thereof.
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- Specific requirements for disclosures to prospective clients/residents.
- Standardized definitions of key terms (including “supportive services”, “health care services”)
- Lease or Service termination requirements including appeal rights and requirements for transfers to new care settings.
- Applicable standards would be applied to all, or a portion of a building, where services are provided.
- Administrators of Assisted Living facilities should meet training and certification requirements.
- One licensed entity will generally be responsible for regulatory compliance for all services offered by the facility or provider, even if subcontracted to other organizations (housing, health care services, support services, etc.). The term “arranged health care provider” should also be statutorily defined.

Additional sections of the proposed licensure law will be drawn from the further detail offered by the Dementia Care Standards, Electronic Monitoring, and Consumer Rights work groups below.

## Certification of Dementia Care Units

### Background

- Dementia is a general term for memory loss and other cognitive abilities serious enough to interfere with daily life.
- Alzheimer's disease is a degenerative brain disease and the most common form of dementia.
- Alzheimer's is a progressive disease, where dementia symptoms gradually worsen over a number of years. In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment.
- 94,000 Minnesotans living with Alzheimer's.
- 1 in 10 people age 65+ has Alzheimer's dementia. 1 in 3 people age 85+ has Alzheimer's dementia.
- 60% of people with dementia live in the community, 25% of whom live alone.
- Individuals diagnosed with Alzheimer's live for an average of 4-8 years, some as long as 20 years.
- Long duration and high care needs associated with Alzheimer's means many individuals living with the disease are high users of long-term care.
- Some people living with dementia require increasing assistance with activities of daily living (ADLs) such as bathing and dressing, and independent activities of daily living (IADLs) such as cooking and managing finances.
- Not all people living with dementia require special services, particularly those in the early stages of the disease.
- For some people living with dementia, there may come a time when their individual needs cannot be met in a particular setting; the progression of the disease exceeds the scope of services offered in some settings.
- 60,000 people living in Assisted Living facilities in Minnesota
- 28,000 residents in Nursing Homes in Minnesota
- Approximately 42% of residents in Assisted Living facilities have dementia
- Approximately 61% of residents in Nursing Homes have dementia
- A little over a third (625 of 1,718) of Housing with Services facilities in Minnesota are registered as special care units, i.e. considered dementia or memory care.
- People living with dementia are served outside of special care units as well.

### Definitions

How terms are used in this report (not recommended statutory definitions):

- Assisted Living – means a long-term care setting licensed under the contemplated Assisted Living License.
- Dementia – is an umbrella term including Alzheimer's dementia and other dementias.
- Dementia care setting – means any assisted living facility that secures, segregates, or provides a special program or special unit for residents with Alzheimer's disease or other dementias or that advertises, markets, or otherwise promotes the establishment as providing specialized care for Alzheimer's disease or other dementias or “memory care.”

## Problems

- Minnesota guidelines and standards for dementia care are weak and vague.
- Individuals and families experience confusion understanding complex regulatory environment, mix of statutes related to Housing with Services/Assisted Living and Home Care.
- In addition to complex laws in different sections of Minnesota statute, some laws are vague, making it difficult for providers to understand the statutory requirements or how they are expected to meet expectations, and they receive inconsistent or conflicting information from Home Care & Assisted Living Program surveyors and Office of Health Facility Complaints investigators
- LTC ombudsman representatives are seeing an increase in concerns and problems at Housing with Services/Assisted Living settings related to dementia care.
- MDH Home Care & Assisted Living Program regulators do not have the authority to address some of the serious problems observed at Housing with Services/Assisted Living settings in survey process, and resources to conduct surveys are not adequate to meet current statutory requirements.

## Vision

- Minnesota law and regulations will ensure that all long-term care settings serving people living with dementia:
  - Provide person-centered dementia care based on thorough knowledge of the care recipient and their needs;
  - Advance optimal functioning and high quality of life;
  - Incorporate problem solving approaches into dementia care practices; and
  - Provide a safe environment while recognizing each resident's autonomy and person-centered care needs, and a stable environment with minimal involuntary moves, which can be particularly difficult for a person living with dementia.
- People with dementia may live in settings that are integrated with individuals that do not have the same needs on in dementia-specific care settings.
- MDH will have appropriate authority and adequate financing and staff resources for consistent and timely surveys and enforcement.
- Residents across Minnesota will maintain access to high quality dementia care.
- Dementia care standards will align with the Home and Community Based Settings Rule standards to support continued access to Medical Assistance waiver funded service.

## Challenges

We discussed many related issues that we recognized we could not overcome in our limited time focused on dementia care standards, but want to identify them as existing challenges. In some cases, there is work happening elsewhere to address these issues.

- Workforce – difficult to recruit, retain, train adequate staff.
- Increased costs associated with additional, new regulation.
- Fluctuations in the long-term care market, i.e., the natural ebb and flow of business in long-term care.

- Elderly Waiver payments may not be enough to cover costs associated with people living with dementia.

## General Recommendations

These recommendations were developed in consideration of the simultaneous work happening in the Assisted Living License Work Group regarding a new license framework. These recommendations should be considered to ensure high quality care for people living with dementia under the new license framework, whether that is in a general population (some people with dementia, some people without) or within a dementia care specific setting. Areas of agreement and disagreement are noted, as well as topics requiring further discussion.

Agreement:

- People living with Alzheimer's disease or other dementias are not required to reside in a dementia care setting.
- There should be additional license or certification requirements – i.e. minimum standards and disclosure – for dementia care settings.

Further discussion:

- Since people living with dementia will live in all types of long-term care settings, all assisted living settings should meet minimum dementia training requirements.

## Implementation

Our group recognized and contemplated the difficulties related to how new minimum standards are implemented, in conjunction with the new assisted living license, without hindering access to living options for people living with dementia. We did not have sufficient time to make recommendations about implementation, but here are some issues we discussed/questions we asked but did not answer.

- How and when does the state require minimum standards to be met for new construction settings?
- Do we have a base understanding of what housing and service models exist currently and do we know what would be required of providers to ensure compliance with any new standards?
- Should these new dementia requirements be effective immediately or phased in over a period of time?
  - If phase-in is allowed, how do consumers know when and how that is happening in a particular setting?
  - What is the right time-frame by which all settings must comply with minimum standards?

## Minimum Standards/Requirements for Dementia Care Settings

Agreement:

- Should not be in conflict with nursing home dementia standards. Standards for dementia care in Assisted Living need not mirror current nursing home regulations but should take the general approach into account so the standards for each setting do not conflict.
- Staff have the skills, training, and education to assess and provide care for a resident population with dementia. (See “Training” for detailed info.)
- Disclosure to regulators, the public, residents and families on issues related to being a dementia care setting. (See “Disclosure” for detailed info.)
- 24-hour awake staff, but further discussion required regarding “on-site.”

Further discussion:

- Activity programming based on physical and cognitive abilities and interests of residents, takes into consideration the resident’s cognitive ability, memory, attention span, language, reasoning ability, and physical function, and includes a person-centered plan for engaging residents in programming.
- Behavior support plan that emphasizes nonpharmacological practices to address behavioral and psychological symptoms of dementia (BPSD).
- Medical management to maximize health and well-being for people with dementia, including when nonpharmacological measures fail, medications, including antipsychotics, which may be necessary and appropriate to relieve the person with dementia’s distress.
- Physical environments to promote safety and minimize confusion and overstimulation, including secure settings responsive to person-centered assessed needs.

## Disclosure for Dementia Care Settings

This language builds on/edits disclosure requirements in Minn. Stat. 325F.72 for special care status.

- Subd. 1: To whom disclosure is required
  - Further discussion: MDH will review disclosures as part of survey process.
  - Agreement: Will be publicly available
- Subd. 2: Content
  - Add to (2): Criteria for who can live there
    - Further discussion: Pre-admission, admission and discharge info/the process and criteria for placement within, transfer/discharge from a dementia care setting if needed
  - Add to (4): Staffing credentials
    - Further discussion: Staffing patterns based on the needs of the patient mix and needs at the time, staff coverage
    - Disagreement: Staff to resident ratios for all night shifts
  - Add to (5): Physical environment
    - Agreement: Emergency procedures/safety plans for unique challenges faced by residents with dementia
    - Agreement: MAARC phone number and other resource list
    - Further discussion: Identify any minimum standards (as outlined in 2019 new statutes) not currently met and a timeline for meeting them. [Consider as a part of



minimum dementia standards implementation and sunset after mandatory compliance date.]

- Subd. 4: Remedy
  - Agreement: Give authority to MDH to enforce by penalty/suspending/terminating license.
  - Further discussion: Whether MDH should be given authority in addition to or instead of the Attorney General.

## Training for all Assisted Living Settings

This language builds on existing training statutes for home care and housing with services.

### Training

- Agreement:
  - Dementia training should incorporate principles of person-centered dementia care including knowledge of the person, their history, interests, abilities and needs; advancement of optimal functioning and a high quality of life; and use of problem solving approaches to care. New and existing care providers should be trained adequately and appropriately to best address the needs of the population of care recipients they serve. Training should also be culturally competent, both for the provider and the care recipient.
  - Require dementia training for all care providers employed by an assisted living facility and who are involved in the delivery of care or have regular contact with persons with Alzheimer’s disease or related dementias.
  - Establish a system to support and enforce continuing education on dementia care.
  - Allow portability of completed dementia care training across employment settings.
  - Require an evaluation of staff competency through demonstration of skills and knowledge gained through training, but further discussion is required as to whether this should be monitored by MDH.
- Further discussion:
  - Use a culturally competent training curriculum that incorporates principles of person-centered care and how to best address the needs of care recipients.
  - Ensure trainers meet minimum requirements to qualify as instructors of dementia care curriculum.
  - MDH formally monitors/evaluates dementia training programs as part of assisted living licensing and ensure compliance with state dementia training requirements.
  - Shorten the timeframe from date of hire until dementia training must be completed.
- Disagreement:
  - Increase total hours of staff training, including annual training
  - Require direct supervision for direct care until hours are completed.

### Curriculum

- Build on existing training requirements in Minn. Stat. 144D.065 for housing with services, to ensure initial training covers the following topics:

- Agreement:
  - Dementia, including the progression of the disease, memory loss, psychiatric and behavioral symptoms.
  - Strategies for providing person-centered care.
  - Communication issues.
  - Techniques for understanding and approaching behavioral symptoms, including alternatives to physical and chemical restraints.
  - Strategies for addressing social needs and providing meaningful activities.
  - Communication of information on how to address specific aspects of care and safety unique to people with dementia (e.g., pain, food and fluid, wandering).

## Other Guidelines

Our group discussed these items in depth, and while we did not feel they rise to the level of being a minimum standard that must be met, we felt they should be considered as guidelines, considerations or best practices for dementia care settings. In some cases, we struggled to define what higher bar should be met for dementia care over what we understand is being recommended for all residents in the Assisted Living License discussion.

- Agreement:
  - Provide assistance, education and coordination of services for transitions to new setting that can take care of a resident's person-centered care needs.
  - Consideration of enriched environments that facilitate engagement with animals, the outdoors, children, etc., based on the interests of the individual.
  - Staff collaboratively assess, plan, and provide coordinated care, including any restrictions based on assessed needs of an individual. Initial assessment should include gathering of personal history and interests of the individual that will be shared with staff to support awareness and person-centered care and programming.
- Further discussion:
  - To what extent coordinated care must be consistent with current advances in dementia care practices.

## Issues to Relay to Other Work Groups for Consideration

- Assisted Living Licensure – Generally these ideas/recommendations are to inform the work of the Assisted Living License Work Group. We did not address all of these areas because we understand that they will be covered in the AL license discussion:
  - Assessment and care planning basics.
  - Transitions in care.
  - Physical plant standards.
- Consumer Rights—We understand they are working on:
  - Consumer rights regarding discharges/terminations.
- Assisted Living Report Card—Should consider inclusion of:
  - Use of antipsychotic medications.
  - Non-medical interventions for behavioral expressions.
  - Therapeutic activities.

- Safe and supportive environments.
- Or all minimum standards for dementia care settings.

## Participants

Alzheimer’s Association Minnesota-North Dakota Chapter, Leading Age Minnesota, Care Providers of Minnesota, individual long-term care providers, paid direct caregivers, Minnesota Elder Justice Center, Office of the Minnesota Ombudsman for Long-Term Care, Minnesota Department of Health, Minnesota Department of Human Services, individual dementia consultants, individual elder Law attorneys

## Resources

Discussions between members of this work group.

[Alzheimer’s Association Dementia Care Practice Recommendations:](#)

[Dementia Care: The Quality Chasm](#)

[The Joint Commission on Dementia Care Accreditation and Certification](#)

## Person-Centered Focus is the Core of Quality Dementia Care

We referenced the following image from the Alzheimer’s Association’s care practice recommendations, which outline recommendations for quality care practices based on a comprehensive review of current evidence, best practice and expert opinion.



## Electronic Monitoring

### Summary of the Process

The Minnesota Elder Justice Center facilitated the electronic monitoring work group, which held over nine meetings since the middle of September 2018.<sup>1</sup> The work group built off the Residential Care and Services Electronic Monitoring Work Group Report submitted to legislature January 16, 2017; different language introduced in the 2018 legislative session; and examples from other states.<sup>2</sup>

We looked at over 15 specific topics related to electronic monitoring. For each topic, we had at least two in-depth conversations and looked at past legislative language when applicable. We did not “vote” on topics or sample language related to topics, but tried hard to note all areas of general consensus and areas of disagreement throughout the process. For purposes of this report, “general consensus” does not necessarily mean there was unanimous agreement, but indicates strong support for the issue.

### Structure of this Report

This report presents all of the topics discussed by the work group, and presents them in order that they might appear in a statute. There is general consensus that Minnesota should have a comprehensive law that allows for electronic monitoring in long term care facilities, and we believe this report goes a long way in providing the rational and sample language for such a law.

We do not anticipate to cover every issue or questions that may be raised during the legislative process, but we intend this report to serve as reference for lawmakers when reviewing issues that have been thoroughly discussed and thought about in this process. For each topic, this report includes:

- A detailed summary about the work group’s discussions regarding the topic. This includes areas of agreement and disagreement and reasons for the differences in opinion
- Sample statutory language. For some topics, there is more than one version of sample language so as to reflect the areas of disagreement on the issues.

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<sup>1</sup> The following entities participated in a majority of the work group meetings: ARC Minnesota, Care Providers of Minnesota, Elder Voice Family Advocates, Leading Age Minnesota, Minnesota Elder Justice Center, Minnesota Department of Health, Minnesota Department of Human Services, and staff from partisan and non-partisan offices of the Minnesota House and Senate.

<sup>2</sup> View the 2017 report, which includes examples from other states, at: <http://www.health.state.mn.us/divs/fpc/rcworkgroup/index.html>. The language examined from 2018 came from SF 3437 found here: <https://elderjusticemn.org/wp-content/uploads/2018/12/3437-1.pdf> and CCRSF 3656 found here: <https://elderjusticemn.org/wp-content/uploads/2018/12/3656.pdf>.

- Comments, when applicable, as to why certain words or language was included or omitted from the sample language.

## Definition of Electronic Monitoring Device

The definition of a device sets the parameters of what this law is regulating. Because an electronic monitoring law will place responsibilities upon those consenting and placing devices in rooms, and upon other parties, it is important that the parameters of what devices we are actually talking about are clear. For example, the working group imagined that anything from bed sensors, to artificial intelligence (i.e. Amazon Alexa), to handheld devices may at one point capture information a private room. When should, then, a device actually trigger the rights and responsibilities encompassed in the law?

The working group agreed that the definition of a monitoring device is a crucial part of any electronic monitoring law. The definition should consider three key questions: (1) what device is used, (2) what is the broadcast and recording/archiving ability of the device, and (3) what is the purpose of the device.

The sample language reflects general consensus that the Minnesota definition should be broad enough to encompass changing technology, but also narrowly apply only to devices that are placed to monitor the resident.

This definition tries to find that balance by excluding devices that capture audio/video (such as computer camera used for skype) but are not used for monitoring and devices that monitor (bed sensors) that do not capture audio or video.

### Sample Language

"Electronic monitoring device" means a camera or other device that captures, records, or broadcasts audio, video, or both, that is placed in a resident's room or private living space and is used to monitor the resident or activities in the room or private living space.

### Comment

The term "placed" is used instead of other verbs that were considered (including "installed") in order to account for devices that may not be technically mounted or otherwise installed in the room. The term "placed" should be used consistently throughout whenever language is referring to the placement or intended placement of the camera.

The work group considered various ideas for the phrase "monitor the resident or activities." This is different language than what was included in SF 3437 and CCRSF 3656, as the phrase "monitor the resident or activities" captures the more expansive purpose of what these monitoring devices may be set up for. In addition to allowing someone to see and hear the resident, devices may be placed in rooms to monitor the care being provided to a resident and to ensure the safety of the resident or resident's belongings, and the word activities helps capture that more expansive goal.

## Definition of Resident Representative

There was little controversy among work group participants in recognizing that a resident with capacity to consent, should be able to place a monitoring device his or her own room. The issue becomes more difficult when another person is consenting on behalf of the resident. Work group participants anticipate that many situations implicated by this law will involve a resident lacking capacity and so it is critical to allow another person to consent on behalf of a resident lacking capacity. The key is to find the right balance in defining who can consent on behalf of such a resident.

If the definition is too narrow, it may prevent a resident's advocate, working in good faith, from protecting the resident through the placement of an electronic monitoring device. If the definition is too broad, it may allow for an individual, or individuals with a more tenuous connection to the resident to be making critical decisions regarding their privacy and safety, and create confusion for licensed facilities and regulators obligated to protect the privacy rights of the resident.

The work group generally came to general consensus that the language of resident representative, as defined in federal regulation, accurately captures the universe of persons that should be allowed to consent on behalf of a resident for purposes of a camera.<sup>3</sup> That includes a court appointed guardian, a health care agent, or a person chosen by the resident (generally upon admission – but not limited to that timeframe).

The work group had lengthy discussions about the scope of this third category (person chosen by the resident). The federal regulation does not indicate *how* someone is designated and/or how the how anyone might actually know someone is designated as this type of resident representative. Some members of the work group noted this ambiguity could be intentional, as a person may want to change who the resident representative is or may not have had the opportunity to designate someone upon admission. Others noted, however, that if the resident lacks the ability to communicate, it would be impossible to verify if a person was truly chosen by the resident if it is not noted somewhere in the file.

### Sample Language

"Resident representative" means a court-appointed guardian, health care agent under section 145C.01, subdivision 2; or a person chosen by the resident and identified in the resident's records on file with the facility.

### Comment

The first two categories are already recognized in law. The specific statutory reference to health care agent is to help clarify any ambiguity about who this person might be, because in practice there is often confusion and conflation between health care agents, someone acting as attorney in fact under a power of attorney document, and other legally-designated decision makers.

The language regarding "identified in the resident's file" is designed to add more clarity about how a resident representative is designated. It intentionally does not prohibit a person from

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<sup>3</sup> See 42 § CFR 483.5.

changing the resident represented any time through the duration of their residency in the facility. Work group members noted that there is not necessarily law on point that requires a provider to ask a resident to identify a resident representative, and thus they may never be given the chance to designate someone in the file. There was not agreement on whether or not such a requirement is needed, advisable, or what exactly it would entail.

## Definition of Facility

The work group spent considerable time discussing the range of facilities where this law may be applicable. While the work group briefly discussed simply aligning the scope of this law with the forthcoming assisted living licensure framework, it was decided that the timeframe for that framework would be too slow to accommodate this law. The work group did agree that the scope of this law should apply to whatever final framework is developed for assisted living license (and may need updating if they do not align right away).

While there was general consensus that this law should apply to nursing homes, there was not consensus on how broad to draw the line within the umbrella “housing with services” designation. All members agree that the final scope should be aligned with the assisted living licensing framework that is to be developed in other legislation. However, as described above, the timeframe for the finalization of such a framework is unknown, so the work group agreed that proposed legislation should specify what facilities this new law should apply to.

Some work group members believe that the rule should apply to all housing with services. Under this reasoning, the requirement and protections afforded under this law should be extended to all settings where housing and services are delivered. Others believe that the rules should only apply to those housing and services operating under the MN. Stat. § 144G assisted living title protection statute. Under this version, several hundred settings that have not chosen such a designation would be left out of this law. It was pointed out that those other settings provide an array of services to a diverse array of individuals and their representatives have not been significantly involved with this work group. The assisted living designated settings generally cater to older adults seeking assisted living services and represent the bulk of the facilities where stakeholders see the need for clarity around electronic monitoring laws.

Finally, the work group also considered whether the law should cover two other settings (swing beds and home care services in someone’s own home), but reached general consensus that they should not be included. Swing beds (beds in hospital settings that are designated and utilized as skilled nursing beds) would likely require outreach to hospital stakeholders and may raise various concerns that would be outside the scope of the residential services settings contemplated in this law. Extending the law to cover all homecare services would include people living in their own homes receiving licensed home care services that are not registered housing with services. Because the breadth of this change would be sweeping (consider that perhaps personal care attendant services would also implicate the law under this reasoning), and stakeholders from those industries were not present, the work group reached general consensus that the law should only apply to homecare services when provided in a setting covered by 144D or 144G.

### Sample Language – Version 1

"Facility" means a facility that is licensed as a nursing home under chapter 144A or as a boarding care home under sections 144.50 to 144.56, a registered as a housing with services establishment under chapter 144D, or the licensed homecare agency providing services to a resident of an establishment registered under chapter 144D.

### Sample Language – Version 2

"Facility" means a facility that is licensed as a nursing home under chapter 144A or as a boarding care home under sections 144.50 to 144.56, a registered as a housing with services establishment under chapter 144D that is also subject to chapter 144G, or the licensed homecare agency providing services to a resident of an establishment registered under chapter 144D that is also subject to chapter 144G.

### Comment

The intent of this definition is to cover both the housing with services establishment that registers under 144D and/or 144G and the home care agency providing services. Because housing and services are regulated separately under current law, this type of specificity is necessary until there is a single license for Assisted Living.

## Electronic Monitoring Authorized

There is general consensus that the statute should explicitly allow for residents to be able to use electronic monitoring in their rooms. Currently, because of confusion regarding the current state of the law, there is an open question as to whether a resident or someone acting on their behalf can place a monitoring device, or if a facility can simply ban the use of any recording devices in the facility. The electronic monitoring law should include language to expressly clarify this current ambiguity in the law.

### Sample Language

**Subd. ( ). Electronic Monitoring Authorized.** (a) A resident of a facility or the resident's representative may conduct electronic monitoring of the resident's room or private living space through the use of an electronic monitoring device or devices placed in the room or private living space as provided in this section.

(b) Provisions in this section do not apply to monitoring technology authorized in HCBS services under sections 256B.0913, 256B.0915, 256B.092, and 256B.049.

(c) Monitoring technology identified in this section may not be reimbursed using HCBS services identified in sections 256B.0913, 256B.0915, 256B.092, and 256B.049.

### Comment

Both SF 3437 and CCRSF 3656 included authorizing language, but approached it differently. SF 3437 stated that a facility must authorize monitoring. Paragraph (a) reflects language from CCRSF 3656 that authorizes the resident or resident representative to conduct monitoring in accordance with the section. As an authorizing section, most in the work group felt it was clearer to give the authority to monitor directly to the resident or resident representative, rather than indirectly giving them authority by requiring the provider to allow the monitoring.



Paragraphs (b) and (c) were suggested by the Department of Human Services (DHS) and are intended to clarify the interaction of this law the other monitoring requirements within the Home and Community Based Services (HCBS) program funded and regulated by DHS.<sup>4</sup>

## Resident Consent to Electronic Monitoring

The work group agreed that the statute should address three types of consent for purposes of placing an electronic monitoring device: consent by the resident, consent on behalf of the resident by a resident representative, and consent by a roommate (if applicable).

Consent by a resident who has capacity to consent is the easiest situation to address in the law. The work group reached general consensus that if a person has capacity and wants to place an electronic monitoring device in their own room or private living space, they can do so. The main question for the law to resolve, is whether the resident must confirm this consent in a written consent form (even if they then do not have to give that form to anyone). Issues concerning consent documentation and notification (including sample language) are addressed in part 10.

## Resident Representative Consent to Electronic Monitoring

One of the most important concepts for an electronic monitoring law to consider is under what circumstances can someone consent *on behalf of* the resident. While the definition of resident representative helps clarify the universe of persons who can fulfil this role, the law should also spell out the steps necessary for that person to provide such consent.

There is general consensus that a starting principal for consent by the resident representative is that the resident him or herself still have an opportunity to know about and disallow monitoring if they choose. There is not full agreement about how that is to be done. The most obvious solution is that the resident representative must go directly to the resident and explain why monitoring is being considered, what will be placed in the room, and what conditions or limitations the resident may want on the monitoring.<sup>5</sup>

During this process, the law should allow the resident to stop any proposed monitoring by expressing their affirmative objection in a variety of possible ways. These added protections come from a recognition that monitoring a resident's private space represents a unique responsibility not necessarily contemplated when a resident representative was appointed (via guardianship) or designated (via healthcare directive or resident representative).

The work group noted practical issues if a resident chooses to place conditions or restrictions on the monitoring (such as turning off during private cares). Who is responsible for doing this and what happens if the instructions are not followed. The sample language remains silent on

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<sup>4</sup> DHS CBSM on monitoring technology can be found here:

[http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\\_DYNAMIC\\_CONVERSION&dDocName=dhs16\\_180346&RevisionSelectionMethod=LatestReleased](http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&dDocName=dhs16_180346&RevisionSelectionMethod=LatestReleased).

<sup>5</sup> The primary concern about this requirement relates to section 9 in this report (who receives notice of monitoring). If a resident representative is required to both have the conversation with a resident and submit a notice form to the facility regarding that discussion, there is concern that the process would be overly scrutinized and/or be a target for retaliation.

this issue, though it was suggested the consent form could clarify that it is the resident and/or their representative's responsibility to make sure the conditions are followed. The work group speculated that in some circumstances the resident representative could work with the provider (though there was not agreement about requiring a provider to do so) or that some technology might allow for customized/remote controls to help with these issues.

Another difficult area was determining exactly when a resident was incapacitated so that the resident representative could consent on his or her behalf. There were concerns that the use of a physician as contemplated by the sample language (see below) is not always the most reliable or efficient way to determine capacity. While work group members agree that determining capacity is a moving target, there are no other legal alternatives short of sending someone through a guardianship process or having a physician assess capacity. There is general consensus that this law should not encourage guardianship and it would not make much sense to have a law that does not indicate when a resident representative would be allowed to consent on behalf of the resident. Without the sample language regarding capacity, there would be too much confusion/potential conflict if a resident representative is adamant that a person is incapacitated, but others (including possibly the resident) say otherwise.

Finally, the work group had general consensus that the law should account for the possibility that two or more resident representative's may have competing ideas about consent and the placement of the electronic monitoring device. The law could account for this by creating a hierarchy, such that the legal guardian overrules either of the other two representatives and the healthcare agent overrules the resident representative indicated in the resident's file. The work group did not develop sample language relating to this hierarchy of authority but had general consensus that it will be important to develop it during the legislative process (see paragraph (f) in sample language below). It was also widely agreed that a competent resident overrules any resident representative, though it is not clear that any further language is needed to clarify this point as a competent resident can simply object as outlined in the sample language below.

### **Sample Language**

**Subd. ( ). Consent on behalf of a resident.** (a) If the resident has not affirmatively objected to electronic monitoring and the resident's physician determines that the resident lacks the ability to understand and appreciate the nature and consequences of electronic monitoring, the resident representative may consent on behalf of the resident. For purposes of this subdivision, a resident affirmatively objects when the resident orally, visually, or through the use of auxiliary aids or services declines electronic monitoring.

(b) Prior to a resident representative consenting on behalf of a resident, the resident must be asked by the resident representative if the resident wants electronic monitoring to be conducted. The resident representative must explain to the resident:

- (1) the reasons for placing an electronic monitoring device;
- (2) the type of electronic monitoring device to be used;
- (3) the resident may place conditions or restrictions on the use of the electronic monitoring device, including those listed in [ ];
- (4) with whom the recording may be shared under this section; and

(5) the resident's ability to decline all recording.

The resident's response must be documented on the notification and consent form.

(c) A resident may set conditions or restrictions for use of the electronic monitoring device, including the list of standard conditions provided in [insert subdivision].

(d) A resident may request that the electronic monitoring device be turned off or the visual or audio recording component of the electronic monitoring device be blocked at any time.

(e) A resident may withdraw the consent made on the resident's behalf at any time by affirmatively objecting to the monitoring.

(f) [Hierarchy of resident representatives]

### **Comment**

The work group added paragraph (b)(1) that had not been in any previous language to ensure that the conversation with the resident includes at least some basic information about why the resident representative is planning to place a monitoring device in the resident's room or private living space.

## **Roommate Consent**

While many residents in long-term care settings have private living spaces, there is consensus that roommate issues must be addressed by the law.

There is general consensus that the roommate consent process should largely, though not entirely, mirror the consent process used by a resident representative. That is – the roommate must be consulted (even if the roommate's resident representative will be consenting on his/her behalf). The work group considered situations where a resident or resident representative may not know whether the roommate has capacity and/or has a representative (or who that person might be). There was not agreement, however, on whether (or how) the law should address these situations.

### **Sample Language**

**Subd. (. Roommate Consent.** (a) Prior to implementing electronic monitoring, a resident or a resident's representative must obtain the written consent of any other resident residing in the room or private living space on the notification and consent form.

(b) If the roommate has not affirmatively objected to the electronic monitoring in accordance with this subdivision and the roommate's physician determines that the roommate lacks the ability to understand and appreciate the nature and consequences of electronic monitoring, the roommate's resident representative may consent on behalf of the roommate. The roommate and a person consenting on behalf of the roommate must be told:

(1) the type of electronic monitoring device to be used;

(2) that they can place conditions on the electronic monitoring device's use, including those listed in [insert subdivision];

(4) with whom the recording may be shared under this section; and

(5) their ability to decline all recording.

(c) A roommate or roommate's representative may consent to electronic monitoring with any conditions of the roommate's choosing, including the list of standard conditions provided in subdivision [add from subd. re: contents of notice]. A roommate may request that the visual or audio recording component of the electronic monitoring device be disabled or blocked at any time.

(d) Consent may be withdrawn by the roommate or roommate's resident representative at any time by submitting written notice to [Depends on what type of notice requirement is adopted].

(e) Any resident currently conducting electronic monitoring must obtain consent from any new roommate before the resident resumes electronic monitoring. If a new roommate does not consent to electronic monitoring and the resident conducting the electronic monitoring does not remove the electronic monitoring device, the facility must remove the electronic monitoring device.

### **Comment**

In Subd. (1)(b), the statute lays out largely the same requirements regarding the process of determining capacity and the safeguards related to this process. The statute gives the roommate the same opportunity to place conditions on the camera's use. The statute does not require the roommate be told the reasons for the placing of an electronic device, though nothing prohibits the resident or the resident representative from offering that information.

The statute clarifies that the roommate must be told of the itemized list whether they are consenting themselves or a resident representative is consenting on their behalf.

The language in (c) mirrors the conditions language in the resident section. The subdivision numbering is blank to account for changes in drafting, but refers specifically to the subdivision that lays out the contents of the consent/notice form. Paragraph (d) is similar to the withdrawal language for a resident who wants to withdraw consent. The person to whom the withdrawal is left open here because it will depend on what the law requires in terms of who the law requires the consent form to be given. Paragraph (e) contemplates a situation in which a new roommate moves into a room where monitoring is already being conducted.

## **Roommate Refusal to Consent, Reasonable Accommodations**

The work group talked about circumstances where a resident's roommate does not consent to monitoring, and the resident or their representative look to the facility to help accommodate the resident's desire for monitoring by offering an alternative (such as changing rooms). Language in SF 3437 described what such an accommodation might look like.

The work group also noted that the term reasonable accommodation could be confusing, as it has a different meaning outside this context. The group did not, however, come up with clearly suitable alternative wording. One possible idea is to just call the subdivision "alternative accommodations."

In sum there are three general options to choose from: general reasonable accommodation, specific definition of what reasonable/alternative accommodation might be, and no reference at all to this concept in the statute.

There was not a lot of push for option 1, and paragraph b of option 2 raised many questions of feasibility. There is general agreement that providers should try and find a creative solution when possible, but no clear agreement about if that should be mandated in statute. There was wide agreement that the roommate should not be the one who has to move or asked to move as part of any accommodation.

### **Sample Language – Option 1**

**Subd. ( ). Reasonable Accommodation.** The facility shall make a reasonable attempt to accommodate the resident or resident representative who wants to conduct electronic monitoring.

### **Sample Language – Option 2**

**Subd. ( ). [Reasonable/Alternative] Accommodation.** (a) If a resident of a facility who is residing in a shared room wants to conduct electronic monitoring and another resident living in or moving into the same shared room refuses to consent to the use of an electronic monitoring device, the facility shall make a reasonable attempt to [accommodate/provide alternatives] to the resident who wants to conduct electronic monitoring. A facility has met the requirement to make a reasonable attempt to accommodate [provide alternatives to] a resident who wants to conduct electronic monitoring when upon notification that a roommate has not consented to the use of an electronic monitoring device in the resident's room, the facility offers to move the resident to another shared room that is available at the time of the request.

(b) If a resident chooses to reside in a private room in a facility in order to accommodate the use of an electronic monitoring device, the resident must pay the private room rate. If a facility is unable to accommodate a resident due to lack of space, the facility must reevaluate the request every two weeks until the request is fulfilled. A facility is not required to provide a private room or a single-bed room to a resident who is not a private-pay resident.

### **Sample Language – Version 3**

No language needed, the statute should stay silent as to reasonable accommodation.

## **Notice of Consent**

Once a resident or a resident representative consents to monitoring, it triggers an important question: should the resident and/or the resident's representative be required to notify the facility by giving the facility a copy of the consent form?

The work group generally agreed that if notice is required, a resident or resident representative would not have to fill out or sign the consent form in the presence of a facility employee/representative. On most other notice issues, however, there was no agreement.

### **Resident Consent Only**

There is not agreement on this issue. Some believe that once a resident consents, there is no reason they would need to give notice to the facility. If that resident fears possible retaliation,

which is the primary argument for not requiring notice to the facility, it may temper their desire to place the electronic monitoring device. Language should be included in the law to prohibit facilities from retaliating, which may allay some resident fears.

Other work group members believe that notice to the facility should be required for every electronic monitoring device placement, as such a policy promotes consistency and provides the clearest avenue for provider facilities to know who put a camera in the room if it is found. A primary reason for requiring notice is so the facility can protect the resident's right to privacy. In this scenario, however, that may be less of a concern as the resident could be seen as waiving privacy rights related to the data captured by the device. That resident should not expect the facility to protect their right to privacy as it pertains to the electronic monitoring device.<sup>6</sup> The work group discussed, but did not develop, language that clarifies a resident waving their right to privacy, though it could be added to the consent form.

Provider participants in the work group also expressed that notification provides an opportunity to protect the privacy of others who may enter the room being monitored (such as residents with cognitive impairment). It also provides an opportunity for communication about concerns the resident/family may have about the provider's services and treatments, including fears that maltreatment is or may be occurring, which would serve the purpose of preventing maltreatment from occurring. Consumer representatives noted that resident's wanting to place an electronic monitoring device may have already tried and failed to raise issues with the facility.

The issue was never fully settled one way or another, and the sample language below allows for this issue to be resolved either way.

### **Resident Representative Consent on Behalf of the Resident**

One of the more deliberated topics was whether a resident representative, upon consenting on behalf of the resident, must notify the facility by giving them a copy of the consent form.

For those wary of a notice provision, the requirement acts as a barrier to placing an electronic monitoring device. In many situations, the underlying reasons for the placement relate to a mistrust or breakdown of communication and a resident or resident representative may be worried about retaliation for placing a device. The work group noted that while retaliation has been discussed in other work groups related to these issues, this particular issue of electronic monitoring device placement will need to be flagged as a particular inflection point.

Additionally, unless electronic monitoring is happening in all rooms, someone seeking to maltreat a resident (i.e. theft or drug diversion) may simply do so in a room they know is not being monitored.

On the other side, proponents of notification note that it is important for the facility to perform their duty of protecting privacy. If they do not know who put in the camera, and one is found,

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<sup>6</sup> The work group noted further discussion on this issue is needed because federal regulations regarding nursing homes may not allow someone to "waive" rights and the privacy protections in those regulations may present conflicts for providers if no-notice is required in the state electronic monitoring law.

how are they supposed to ensure resident privacy?<sup>7</sup> Additionally, without notification, how can a provider and/or regulator be certain that a resident representative met the requirements of the consent provisions in the law? Some providers also noted that a care team may be more apt to provide responsive and quality care if they know a camera is in a resident's room. In addition, notification could, depending on the circumstances, trigger the provider to initiate an external investigation regarding maltreatment. In sum, there are strong opinions on both sides of the issue.<sup>8</sup>

There was significant discussion, therefore, on finding some level of compromise. One area of compromise considered was limiting the notice to a designated person in the facility (such as the facility administrator only). Many observers, including multiple providers, noted that it is simply not realistic to expect that once a monitoring device is found (or even if notice given) that it will remain only known by one person in the facility. Language limiting the notice to a certain person or part of a resident's file, therefore, is not included in this report.

Another area of compromise, reflected in sample language version 2, is notice to a third party. This effort, would require logistical and cost considerations for the third party entity to act as such repository. One idea that was contemplated was that the Ombudsman for Long-Term Care might be able to be the repository. After further reflection however, that office reported that it is not prepared to play that role nor is it really within the scope of that organization's work. It was suggested in the alternative that MDH could be such repository. A provider, seeking to discharge their duty to privacy, would contact MDH upon finding of a camera to ensure that the proper consent form was filed.<sup>9</sup>

A third area of compromise that was explored was a general rule that requires notice be given to the facility, but to allow for certain exceptions where notice is not required for short periods of time. This sample language reflects a time-limited approach under certain conditions. It also reflects the work group's general agreement that the law should not incentivize a person from holding onto video/audio evidence of maltreatment without alerting authorities.

There is general agreement that when a roommate is involved, the concern for privacy may be heightened and perhaps should outweigh fear of retaliation. In this instance, the work group discussed but did not develop language about ensuring notice to facility when roommate is involved with no exceptions.

### **Sample Language – Version 1**

**Subd. ( ). Notice of monitoring to the facility. (a) Electronic monitoring may begin only after the [resident and/or resident representative] who intends to place an electronic**

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<sup>7</sup> The work group considered, but did not conclude on way or another, that the issue of waving one's right to privacy is more difficult if the resident representative is consenting and also waving privacy on behalf of the resident (as opposed to when a competent resident is waving that right).

<sup>8</sup> The work group also noted that further input from other stakeholders (including employees) who were not part of these discussions may add more perspective on the notice issues.

<sup>9</sup> It was discussed that this concept may need additional language in statute, even beyond what is provided in paragraph (b) of the facility liability subsection described below, but the group did not develop further language on this point.

monitoring device completes a notification and consent form prescribed by the commissioner and submits the form to the facility.

**Comment – Version 1**

The work group considered designating a person within the facility to receive the form. This was in part to consider the issue of “limited” notice as discussed above, but because there was broad consensus that limited notice was impractical and would be ineffective to serve the purpose of limiting possible retaliation (or fears of retaliation), it was not included in the language. It was also decided that designating a specific person in the facility to receive the form would create unnecessary confusion.

**Sample Language – Version 2**

**Subd. ( ) Notice of monitoring to Minnesota Department of Health.** (a) Electronic monitoring may begin only after the [resident and/or resident representative] who intends to place an electronic monitoring device completes a notification and consent form prescribed by the commissioner and submits the form to the Minnesota Department of Health as instructed on the consent form.

**Sample Language – Version 3**

**Subd. ( ). Notice of monitoring to the facility, exceptions to required notice.**

(a) Electronic monitoring may begin only after the [resident and/or resident representative] who intends to place an electronic monitoring device completes a notification and consent form prescribed by the commissioner and submits the form to the facility.

(b) Notwithstanding this section, the [resident and/or resident representative] who intends to install an electronic monitoring may do so [by submitting a notification form to MDH] without submitting a notification and consent form to the facility:

(1) for up to 30 days if the [resident or the resident’s representative] reasonably fears retaliation of the resident by the facility and timely submits a MAARC report and/or police report upon evidence from such electronic monitoring device that suspected maltreatment has occurred;

(2) for up to 30 days if the resident or resident’s representative has already communicated in writing to the facility his or her concerns prompting the desire for placement without a written response from the facility; or

(3) for up to 30 days if the resident or resident’s representative has already submitted a MAARC report and/or police report regarding his or her concerns prompting the desire for placement.

**Comment – Version 3**

There is not agreement about the scope of this language. Some work group members believe this type of exception process presents a suitable alternative between notice to facility and no notice to facilities. In paragraph (b), there is an option to require notice to MDH (as per version 2) while not alerting the facility for a time-limited period. If adopted, the form would likely have to indicate clear instructions about the 30 day rules and the reporting requirements contemplated by this language. The work group noted there may be some additional practical



considerations with this version, but did not have enough time to fully discuss all the possible iterations or changes to this sample language.

#### **Sample Language – Version 4**

No language suggested, as no notice of any kind would be required.

## **Notification/Consent Form**

There is general consensus that in order to ensure that consent has been obtained, a template form should be available to the public. Mandating the Commissioner to develop a form would promote standardization of what is included in the form.

#### **Sample Language**

**Subd. ( ). Notification and consent form requirements.** (a) The notification and consent form must include, at a minimum, the following information:

(1) the resident's signed consent to electronic monitoring or the signature of the resident's representative, if applicable. If a person other than the resident signs the consent form, the form must document the following:

(i) the date the resident was asked if the resident wants electronic monitoring to be conducted;

(ii) who was present when the resident was asked; and

(iii) an acknowledgment that the resident did not affirmatively object;

(2) the resident's roommate's signed consent or the signature of the roommate's resident representative, if applicable. If a roommate's resident representative signs the consent form, the form must document the following:

(i) the date the roommate was asked if the roommate consents to electronic monitoring;

(ii) who was present when the roommate was asked; and

(iii) an acknowledgment that the roommate did not affirmatively object;

(3) the type of electronic monitoring device to be used;

(4) any installation needs, such as mounting of a device to a wall or ceiling;

(5) the proposed date of installation for scheduling purposes;

(6) a list of standard conditions or restrictions that the resident or a roommate may elect to place on the use of the electronic monitoring device, including, but not limited to:

(i) prohibiting audio recording;

(ii) prohibiting video recording;

(iii) prohibiting broadcasting of audio or video;

(iv) turning off the electronic monitoring device or blocking the visual recording component of the electronic monitoring device for the duration of an exam or procedure by a health care professional;

(v) turning off the electronic monitoring device or blocking the visual recording component of the electronic monitoring device while dressing or bathing is performed; and

(vi) turning off the electronic monitoring device for the duration of a visit with a spiritual advisor, ombudsman, attorney, financial planner, intimate partner, or other visitor;

(7) any other condition or restriction elected by the resident or roommate on the use of an electronic monitoring device;

(8) a signature box for documenting that the resident or roommate has withdrawn consent; and

(9) a statement of the circumstances under which a recording may be disseminated under subdivision [ ].

(b) A copy of the completed notification and consent form must be provided to the resident and the resident's roommate, if applicable. [The facility must retain the form after receiving it in accordance with subsection [ ].]

(c) The commissioner shall prescribe the notification and consent form required in this section no later than [ ], and shall make the form available on the department's web site.

#### **Comment**

Paragraph (a)(9) could include a more itemized list of the acceptable reasons/outlets for dissemination, such as "I authorize dissemination to legal or investigatory authorities only, media outlets, or any purpose to protect my or other residents health, safety, or welfare." Paragraph (b) will depend on what notice provisions would be adopted into statute.

The language in paragraph (b) will depend on what type of notice is required by the statute.

## **Costs and Installation**

The work group discussed the practicalities of using internet for electronic monitoring. It was noted that in many assisted living or housing with services residencies, residents already contract directly with a cable company and routinely install their own Wi-Fi network using their own internet plan. Other facilities may provide a public Wi-Fi system available to residents and guests. It was noted that too much monitoring on the public network may slow down speeds and that there is not agreement as to what providers must do, if anything, to accommodate monitoring in these situations.

The work group agreed that the language should not be too prescriptive and that the resident should bear the costs related to the device (although not necessarily for the use of public Wi-Fi). It was noted that without broadband or other tools, access may be in an issue for some residents, but it was outside the scope of this work to discuss solutions related to access.

## Sample Language

**Subd. ( ). Costs and installation.** (a) A resident [or resident representative] choosing to conduct electronic monitoring must do so at the resident's own expense, including purchase, installation, maintenance, and removal costs.

(b) If a resident chooses to install an electronic monitoring device that uses Internet technology for visual or audio monitoring, that resident may be responsible for contracting with an Internet service provider.

(c) The facility shall make a reasonable attempt to accommodate the resident's installation needs, including allowing access to the facility's public-use internet or Wi-Fi systems, when available for other public purposes.

(d) All electronic monitoring devices shall be UL-listed.

## Comment

In paragraph (c), there is an open question as to what is reasonable (and who has the burden of showing an accommodation is reasonable) if the public Wi-Fi system cannot accommodate the speeds necessary for monitoring. More language may be necessary if the law is to address these scenarios.

## Notice to Visitors

Most electronic monitoring laws contemplate public signage that would alert visitors, staff, and the public that electronic monitoring is or may be occurring. Some states require the posting of such signage on a resident's door if/when monitoring is authorized in their room.

There was general consensus (though not total agreement) that signage in the public area of the facility (ideally near the front entrance or the most conspicuous public space) indicating electronic monitoring "may be happening" is a good idea. There is general consensus that the law should not require residents or resident representatives to post about any monitoring that may be occurring in the resident's private space – but that such a sign would not be prohibited.

## Sample Language

**Subd. ( ) Notice to visitors.** (a) A facility shall post a sign at each facility entrance accessible to visitors that states "Electronic monitoring devices may be present to record persons and activities."

(b) The facility is responsible for installing and maintaining the signage required in this subdivision.

## Dissemination

It is important that an electronic monitoring law lay out requirements for how a person in possession or control of the video and or audio captured by a device is allowed to share and disseminate that data.

While the work group noted that this topic involves, at some level, the question of "who owns the data," it was decided that this particular law should not (or does not need to) speak directly

to that question. It was widely thought, though not verified with specific research, that the resident and/or resident representative own the device and the data emanating from that device.

The more pressing question, however, that the work group generally agreed the law should address is under what circumstances the data, when controlled by a resident representative, must be or could be shared with others. It was generally agreed that the law should, at the very least, provide an “outer boundary” for when data should be shared. This outer boundary is delineated by the language “health, safety, or welfare”. The reason for the boundary is to respect resident privacy when their safety is not a concern and prohibit sharing of data for distasteful purposes. For example, this outer boundary would prohibit the posting of a video to social media because someone thought it was funny. This outer-boundary approach would leave it to the resident and resident representative to determine what purposes may fall under these guidelines, such as sharing a concerning interaction between a resident and care provider with a media outlet to draw broader attention to the care.

As an alternative, some in the work group think a more narrow approach could be taken, because “health, safety, or welfare” is so broad that it could encompass many things that could be on the borderline between inappropriate to share and yet still in furtherance of the person’s welfare to share. To address this, the work group considered that a resident could narrow the reasons for dissemination, as laid out in the contents of the consent form section.

The work group also discussed enforcement of improper dissemination. The work group considered that criminal and/or civil laws may be implicated by breaching this subdivision, but felt it unwise to create new civil or criminal penalties for specifically violating this subdivision. Instead, the sample language simply indicates that criminal or civil laws may apply to the improper dissemination of this data.

Another issue that the work group discussed, but did not come to any conclusion nor decide to provide sample language for, is the ability for an employee to access/view data. This scenario arises if a provider employer takes negative action against an employee, and the employee believes the data could exonerate, explain, or otherwise aid in their defense against the negative action. The work group agreed that more stakeholders, including those representing employees within facilities, should weigh in on any future discussions of this issue.

### **Sample Language**

**Subd. ( ). Dissemination of data. (a) No person may access any video or audio recording created through electronic monitoring without the written consent of the resident or the resident's representative.**

**(b) Except as required under other law, a recording or copy of a recording made as provided in this section may only be disseminated for the purpose of addressing health, safety, or welfare concerns of a resident or residents.**

**(c) A person disseminating a recording or copy of a recording made as provided in this section in violation of this subsection may be civilly or criminally liable.**

**Comment**

The work group noted that the terms “recording” or “copy of recording” (especially in paragraphs (b) and (c)) may not be broad enough to cover live broadcasting or perhaps other data related to the electronic monitoring that may be important to cover with this section. However, other terms such as “data” were not discussed enough to consider all potential implications of using that word.

## Facility Liability

There is general consensus that the law should relieve the facility from liability in certain circumstances. Because the facility has no control over what the resident or the resident representative choose to do with data from the device, the facility should not be held liable for any such action. The same is true for liability related to the right to privacy.

**Sample Language**

**Subd. ( ). Facility Liability.** (a) A facility is not civilly or criminally liable for the inadvertent or intentional disclosure of a recording by a resident or a resident's representative for any purpose not authorized by this section.

(b) A facility is not civilly or criminally liable for a violation of a resident's right to privacy based solely on the use of electronic monitoring conducted as provided in this section.

**Comment**

As with sample language regarding dissemination of data, it is not clear if the term “recording” accurately captures everything that should be covered, including live-broadcasting or copies of recordings. The work group did not have enough time to fully contemplate additional language addressing those issues.

## Obstruction of Electronic Monitoring

The work group did not fully discuss all of the issues related to intentional obstruction. The sample language was in both SF 3437 and CCRSF 3656.

**Sample Language**

**Subd. ( ). Obstruction of electronic monitoring.** (a) A person must not knowingly hamper, obstruct, tamper with, or destroy an electronic monitoring device installed in a resident's room or private living space without the permission of the resident or the resident's representative.

(b) It is not a violation of this subdivision if a person turns off the electronic monitoring device or blocks the visual recording component of the electronic monitoring device at the direction of the resident or the resident's representative, or if consent has been withdrawn.

**Comment**

An additional sentence to paragraph (b) may be added to clarify that facilities are not *required* to turn off a device or help effectuate any conditions placed on the use of a device. That could read “[T]his language shall not be construed to require a facility to turn devices on or off at the

request of a resident or resident representative or otherwise to assist the resident in fulfilling specific conditions that the resident wishes to place on the use of the monitoring device.”

## Resident Rights and Protections | Penalties

There is general consensus that resident’s ability to place an electronic monitoring device according to the provisions of this chapter should be protected. These sections outline two ways to do that.

First, there was general consensus that there should be language preventing facilities from refusing to admit, retaliating, and preventing electronic monitoring. There was some discussion about whether the concept of retaliation should be further developed here. It was noted that in the context of resident rights in long term care facilities, there are four other applicable areas of law where retaliation is regulated. There is broad array of approaches in these provisions whereby sometimes retaliation is defined in detail (along with who has the burden to prove retaliation). Other times the statute is vague.<sup>10</sup> There is no consensus as to how to approach retaliation in this particular scenario.

There was no consensus on whether the department of health should be required to issue a correction order and/or if the authority to fine for violations of such an order should be included. The sample language is included below, adapted from SF 3437.

### Sample Language

**Subd. ( ). Resident rights and protection.** (a) A facility must not:

(1) refuse to admit a potential resident or remove a resident because the facility disagrees with the potential resident's or the resident representative’s decisions regarding electronic monitoring;

(2) retaliate against any resident for consenting or refusing to consent to electronic monitoring under this section; or

(3) prevent the placement or use of an electronic monitoring device by a resident who has provided the facility with notice and consent as required under this section.

**Subd. ( ). Penalties.** The commissioner of health [may/must] issue a correction order upon a finding that the facility has failed to comply with this subdivision. The commissioner of health may impose a fine up to \$500 upon a finding of noncompliance with a correction order issued according to this paragraph.

### Comment

Language introduced in both SF 3437 and CCRSF 3656 included the phrase “retaliate or discriminate.” The work group generally agreed that the action needing prevention is retaliation and did not include the word discriminate.

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<sup>10</sup> The four other Minnesota statutes include: retaliation related to advocacy by the Ombudsman for Long Term Care (section 256.9742 subdivision 6), retaliation in eviction actions (section 504B.285 subdivision 2), retaliation against a person reporting suspected maltreatment of a vulnerable adult (section 626.557 subdivision 17), and retaliation against someone asserting a right under the Home Care Bill of Rights (section 144A subdivision 1 (22)).

## Consumer Rights Working Group

### 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 Work Group 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 made available on an MDH dedicated website. In addition, comment/input was solicited from each group member via e-mail.

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

The work group 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 work group 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 work group members related to each topic. For points not listed under “areas of agreement,” these are either areas where the work group was not able to finalize discussions regarding agreement or where there was disagreement. More specifics on work group discussions can be found in the work group’s meeting minutes.

## Retaliation in Assisted Living and Home Care Bill of Rights

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:
  - 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.?
  - 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 work group 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 work group did not reach consensus on private right of action.

## Enforcement and Fines in Assisted Living and Other Settings

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. Work group 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:

- Some work group members support court actions for private claims after the death of residents.
- Some work group 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

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 one 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. Work group 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 two contract system (housing and services) may create barriers to knowledge of rights

## Lease and Service Terminations

Aging in place where possible is a priority that has stated throughout work group discussions, including in the Assisted Living Licensure Work Group. Many Consumer Rights Work Group 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 Work Group. There was agreement, however, that this topic should be addressed by the Assisted Living Licensure Work Group.

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 work group.

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

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.

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 work group 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

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 Work Group. Due to time limitations, there was not the opportunity to discuss in detail the issue of informed choice and disclosures in the Consumer Rights Work Group, 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 efforts.

## Other Topics Raised in Work Group Meetings

Below are some additional topics that were raised by work group 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 Work Group has focused on this issue)
- Continuing the collaborative work of MDH work groups
- Home and Community-Based Waivers (e.g., Elderly Waiver) caps and funding
- Recognize consumer rights cross over each work group; each work group should duly note applicable rights to topic or recommend additional rights needed.

## Feedback from All-Group Polling

- In a meeting of all the working groups, there were polls that took place on some of the topics addressed by the Consumer Rights Work Group.
- 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 of 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.Detail on exact polling results may be found in the polling document listed on the MDH working group website.

## Assisted Living Report Card

The Minnesota Department of Human Services (DHS) convened the Assisted Living Report Card work group. The work group met once and identified the areas of agreement listed below. At this meeting, the work group was informed of a contract that has since been finalized between DHS and the University of Minnesota Center on Aging. Through this contract, the Center on Aging will facilitate a process by which the domains and measures for an assisted living report card will be identified.

### Areas of Agreement

- An Assisted Living Report Card is needed and should be pursued as a part of a multi-prong effort to encourage and reward quality in long-term services and supports.
- The Nursing Home Report Card work benefitted from a number of existing data sources to pull from which is lacking for the development of an Assisted Living Report Card.
- Developing an Assisted Living Report Card will take time and should be coordinated with efforts underway for Assisted Living Licensure and Dementia Care Certification.
- The domain ranking exercise completed during the first meeting opened participants' eyes to the difficulty of determining quality domains when faced with individual preferences and underlined the importance of taking time to develop the report card while also coordinating that with efforts of other work groups.

### Recommendations and Next Steps

- Conduct a literature review and environmental scan, including: published literature on nursing home quality measures; grey literature on assisted living measures and domains of quality; a review of state-level efforts regarding assisted living measures; and consultation with experts in aging on this subject. (April 2019)
- Create a database results to existing home and community based services quality frameworks and data collection efforts at the state and national level (for example, National Core Indicators-Aging and Disabilities). Add additional measures to the database based on this analysis. (June 2019)
- Compare the database results to existing home and community based services quality frameworks and data collection efforts at the state and national level (for example, National Core Indicators-Aging and Disabilities). Add additional measures to the database based on this analysis. (June 2019)
- Engage a technical expert panel from academia, policy, and practice spheres to review the proposed measures. Finalize a list of proposed measures that could be shared with a wider group of stakeholders, including prospective and current residents of assisted living and family members. (July 2019)

The feedback of people who reside in assisted living and their family members is a very important component of a valid assisted living report card. DHS will require resources to support this effort. If necessary resources are provided during the 2019 legislative session, DHS could begin survey implementation in October 2019.

## Improving Quality and Safety in Long-Term Care Settings

Most of the work groups were anticipated to complete their work by the end of 2018, however this group focused on improving quality and safety in long-term care settings was continue beyond the end of 2018 and seek to develop a shared vision and charter.

This work group aims to create a system to improve quality and safety in long-term care in Minnesota. The system will foster a culture that enables learning and improvement through data transparency, sharing of successes and challenges statewide, is person-centered and optimizes resident choice, rights, and safety concurrently.

This work group is comprised of a broadly represented and diverse set of stakeholders working across long-term care settings in Minnesota.

- At this time, the scope is not intended to include acute care hospitals or ambulatory clinics—except in scenarios in which quality and safety issues arise related to care settings transitions.
- This group will convene through calendar year 2019, and will be evaluated at year’s end.
- The continuing focus will be specifically on resident quality and safety work that will benefit from collective attention and effort of a broad group of stakeholders.

## Shared Values

The working group developed a shared set of characteristics for the ideal system for long-term care in Minnesota:

- Quality and patient safety information is transparent and easy to understand for residents, families, and providers.
- Is person-centered/person-directed.
- Is fair/just and promotes accountability across all settings.
- Focused on learning where data is available for improvement.
- A sufficient and well-trained workforce.
- The regulatory system supports and promotes improvement in patient safety and quality.
- Standards for safety data and measurement—useful now and into the future.

## Barriers or Constraints

The following are identified by the work group as constraints in the environment today:

- Workforce challenges – worker shortages and high turnover
- Regulatory system that does not enable a learning culture
- Current terminology and definitions preclude validation of experiences
- Competing priorities for the energy and time needed to achieve change
- Underlying societal and demographic issues
- Challenge including front line staff and residents in the discussion societal issues and scope—many more incidents happen in family/community than care settings

## Draft Recommendations

The work group aims to move from general exploration of broader topics to specific improvement projects. The work group will identify and select projects for collective action that have measurable improvement. Potential projects include:

- Data availability and use,
- Tools and guidance to enable accurate and comprehensive reporting, and
- Advancing a culture of safety.