

# Nursing & Assisted Living Facility Professional

"NEWS AND VIEWS YOU CAN REALLY USE"

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SENT EACH MONTH TO YOU AS A MEMBER OF THE HEALTHCARE HEROES

## THE HAT ADVANTAGE by Rebecca Adelman

### Overview of the Report to the National Advisory Council on Alzheimer's Research, Care, and Services



In October, 2018, the first National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers (the Summit) was held and the report to the Advisory Council on Alzheimer's Research, Care and Services presents the results of the Summit. It is sponsored by

the U.S. Department of Health and Human Services and the Foundation for the National Institutes of Health through private sector support. The complete report can be found at <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>. The idea for the Summit grew out of similar summits held by the National Institute on Aging's (NIA) Alzheimer's Disease Research Summits and the National Institute for Neurological Disease and Stroke (NINDS) Alzheimer's Disease Related Dementias Summits. These conferences are coordinated planning efforts that respond to the National Plan of the U.S. Department of Health and Human Services to Address Alzheimer's Disease, first released in 2012 and now updated annually. (see <https://aspe.hhs.gov/national-plan-address-alzheimers-disease>).

As a person who is providing care to my father who is living with dementia, the Introduction to the Summit report was compelling.

"Persons living with dementia and their caregivers confront significant emotional, physical, and financial stress. As dementia progresses, often over many years, individuals with the condition experience physical, cognitive, and emotional changes that affect the quality of their daily life and ability to remain engaged with meaning and purpose. The lived experience of dementia, adaptive processes of individuals, and perceived and structural stigma are important aspects of the disease process. Caregivers provide the majority of care for people with dementia in the community. These individuals often do not identify themselves as such; they may be a spouse, child, parent, or friend helping a person whom they care about. However, the intensive support that is typically required for a person with dementia as the condition progresses can impact the caregiver's emotional and physical health, well-being, and ability to work. Caregivers often report symptoms of depression and anxiety, financial strain, and have poorer health outcomes than their peers who do not provide such care."

There were six primary sessions at the Summit that formed the

basis of recommendations.

I. Research on Care Needs and Supportive Approaches for Persons with Dementia: This session explored research related to care and support for persons with dementia, including mitigating behavioral symptoms, understanding care in varied settings, and caring for those living alone with the condition.

II. Research on Supportive Approaches for Family and Other Caregivers: This session focused primarily on how caring for a person with dementia affects the caregiver and what is known about effective ways to support caregivers, including examples of effective interventions, common elements of these interventions, and areas where more research is most needed.

III. Involving Persons with Dementia and Caregivers as Members of the Research Team: This session examined important reasons for including persons with dementia and caregivers as members of the research team in studies of dementia care, services, and research, and challenges that researchers may face in doing so. These challenges included deciding which parts of the research process persons with dementia and caregivers would participate in, determining how to identify and recruit people with dementia and their caregivers to serve as co-researchers, and establishing how to effectively engage them as co-researchers.

IV. Involving Persons with Dementia as Study Participants: This session addressed key issues related to involving persons with dementia as participants in research on care and services, including evaluating their capacity to respond to particular research questions, recruiting participants, and understanding the processes of informed consent and assent/dissent to participate in research.

V. Research on Models of Care for Persons Living with Dementia and Their Families Across the Disease Trajectory: This session examined comprehensive models of dementia care, factors that may be important to successful implementation, evidence about the effectiveness of various models, and areas where further research is needed.

VI. Thinking Outside the Box: This session was intended to encourage the field to reconsider how it does research on dementia care, services, and supports, evaluate the strengths and limitations of the methods currently used in this research, and think of new ways to do research that would show clearer, faster results.

*Continued on page 2*

While the Summit produced 694 recommendations. These recommendations we then combined, consolidated and organized into 12 major themes.

- 1. Heterogeneity of Persons Living with Dementia and their Caregivers**
- 2. Research Methods to Develop More Effective Dementia Care, Services and Supports**
- 3. Caregiver Relationships, Roles, and Networks**
- 4. Clinical Approaches and the Lived Experience of Dementia**
- 5. Engaging Persons Living with Dementia and Caregivers in Research**
- 6. Dementia-Related Terminology, Nomenclature, and Stigma: Words Matter**
- 7. Comprehensive Models for Dementia Care, Services, and Supports**
- 8. Strategies for Scaling and Disseminating Existing Evidence, Drawing Upon Implementation Science**
- 9. Living Places, Physical and Social Environments, and Processes of Care for Persons with Dementia, Including Those who Live Alone**
- 10. Financial Burden and Out-of-Pocket Costs to Persons Living with Dementia and their Caregivers**
- 11. Ensuring an Adequate and Qualified Workforce to Support Persons with Dementia and their Caregivers**
- 12. Technology to Support Persons with Dementia and their Caregivers**

I'll provide a brief overview of the recommendations made at the Summit for each of the 12 themes. Further reading of the report is encouraged. Further, additional pursuit of the following areas was identified at the Summit:

Based on the recommendations received from participants in the Summit, additional conferences or workshops are critical to pursue in the following areas:

- Care and services for early stage dementia.**
- Care and services for late stage dementia and end-of-life.**
- Defining technology and better understanding the different uses of technology for care of persons with dementia.**
- Providing services to those who lack access to the health care and/or long-term care systems**

As an overview of the recommendations made related to each Summit themes, please consider:

### **1. Heterogeneity of Persons Living with Dementia and their Caregivers**

*Recommendation 1: Develop accurate, up-to-date descriptive information about the characteristics, care needs, and services used by persons living with dementia and their caregivers.*

*Recommendation 2: Conduct research to increase knowledge about differences in dementia trajectories.*

*Recommendation 3: Analyze available descriptive information to*

*increase understanding about disparities among persons living with dementia and their caregivers.*

*Recommendation 4: Disseminate information to all relevant stakeholders about differences and disparities among persons living with dementia and caregivers.*

### **2. Research Methods to Develop More Effective Dementia Care, Services and Supports**

*Recommendation 1: Use innovative research designs to increase the generalizability of research findings and speed up dissemination of effective dementia programs and services to real-world settings.*

*Recommendation 2: Adopt or develop research methods to study complex, multicomponent programs and services intended to accommodate the many factors that affect care and service needs of persons living with dementia and their caregivers.*

*Recommendation 3: Increase the collection of self-reported data from persons living with dementia and develop standards for determining which individuals can self-report about which outcomes, at which stages of dementia.*

*Recommendation 4: Involve end-users in the identification of dementia research priorities and relevant research outcomes.*

*Recommendation 5: Develop research measures that are important for studying dementia care, services and supports.*

*Recommendation 6: Develop standards for the evidence needed to determine which programs and services are ready for widespread implementation and dissemination.*

*Recommendation 7: Require research reporting that supports accurate replication of effective dementia programs and services in community and other care settings.*

### **3. Caregiver Relationships, Roles, and Networks**

*Recommendation 1: Identify types of dementia caregivers, their needs, and how they self-identify, study the caregiving course to understand roles, needs, preferences, and both positive and negative consequences.*

*Recommendation 2: Understand care decision-making in caregivers and across dementia trajectories, including how decisions are made about care, use of care plans, living arrangements, and seeking support and social services.*

*Recommendation 3: Identify the impact of dementia stage and severity on caregiver well-being, care challenges and supportive needs, and how heterogeneity of caregiver experience may affect receipt of and participation in programs.*

*Recommendation 4: Conduct a review of the established research on caregiver programs across dementia stages to determine what additional research or evidence would be needed to incorporate these evidence-based programs as a covered benefit.*

### **4. Clinical Approaches and the Lived Experience of Dementia**

*Recommendation 1: Identify determinants of behavioral and psychological symptoms, ascertain how persons living with dementia experience these symptoms, and determine long-term effects of evidence-based programs.*

**Recommendation 2:** Conduct studies that combine pharmacological and non-pharmacological strategies to reduce dementia-related symptoms, including behavioral symptoms and functional and cognitive decline, and determine whether reduction in symptoms can slow disease progression.

**Recommendation 3:** Obtain consensus as to definitions of different cognitive strategies and understand impacts of cognitive training.

**Recommendation 4:** Understand what outcomes are important to persons living with dementia and develop programs and services to derive consensus as to what constitutes person-centered care, and improve measures of quality of care and quality of life.

**Recommendation 5:** Understand adaptive and coping mechanisms used by persons living alone with dementia.

## 5. Engaging Persons Living with Dementia and Caregivers in Research

**Recommendation 1:** Engage persons living with dementia and their caregivers as part of research teams that are studying dementia care, services and supports.

**Recommendation 2:** Develop and evaluate promising practices for increasing engagement of persons living with dementia and their caregivers as part of research teams.

**Recommendation 3:** Evaluate the impact of research engagement of persons living with dementia and their caregivers on the validity, value, and credibility of the research findings.

**Recommendation 4:** Encourage the use of engaged research models in studies of dementia care, services, and supports.

## 6. Dementia-Related Terminology, Nomenclature, and Stigma: Words Matter

**Recommendation 1:** Analyze existing dementia-related terminology to identify confusing and stigmatizing terms, and initiate a process to select or develop terminology that will reduce stigma and support effective communication among individuals and groups.

**Recommendation 2:** Examine current awareness of and perspectives on frequently used dementia-related terms.

**Recommendation 3:** Study planned changes in the definition of Alzheimer's disease (often referred to as "nomenclature" in this context) and evaluate the need for information about the changes for affected individuals and the public.

**Recommendation 4:** Disseminate new and revised dementia-related terminology, monitor uptake, and evaluate impacts on communication among individuals and groups, negative stereotypes, and stigma.

## 7. Comprehensive Models for Dementia Care, Services, and Supports

**Recommendation 1:** Identify the core components of comprehensive models of care for persons living with dementia.

**Recommendation 2:** Identify core outcomes for measuring the effectiveness of comprehensive models of care for persons living with dementia and their caregivers.

**Recommendation 3:** Evaluate and compare comprehensive models of care and develop new models for subgroups of persons living with dementia that are not effectively served by existing models.

**Recommendation 4:** Identify and evaluate features of

comprehensive models of care for persons living with dementia that may affect their real-world feasibility and acceptability in particular communities and geographic locations.

**Recommendation 5:** Examine Dementia Friendly Community models and evaluate their impact on persons living with dementia, caregivers, and communities.

**Recommendation 6:** Disseminate findings from research on comprehensive models of care and Dementia Friendly Community models to potential users, including persons living with dementia and their caregivers, medical, residential, and community-based providers, health care systems, and payers.

## 8. Strategies for Scaling and Disseminating Existing Evidence, Drawing Upon Implementation Science

**Recommendation 1:** To make evidence-based programs and services for persons living with dementia and their caregivers more widely available in communities across the country, researchers and program developers should begin planning for dissemination and sustainability early in the process of program development.

**Recommendation 2:** Conduct research to increase understanding about organizational readiness and capacity to implement and sustain evidence-based programs and services for persons living with dementia.

**Recommendation 3:** Study approaches to optimize working relationships between health care and community-based organizations that are critical to providing the coordinated medical care and social services needed by persons living with dementia and their caregivers.

**Recommendation 4:** Examine dementia-related costs to all payers, the division of costs among payers, and cost shifting.

**Recommendation 5:** Identify payment models and financial incentives to support dissemination and sustainability of evidence-based programs and services for persons living with dementia.

**Recommendation 6:** Develop and evaluate approaches to increase willingness to use, provide, and/or pay for evidence-based programs and services among persons living with dementia, caregivers, and provider organizations.

**Recommendation 7:** Identify methods that individual communities can use to begin planning for the array of care, services, and supports required to meet the needs of that community's residents living with dementia and their caregivers.

## 9. Living Places, Physical and Social Environments, and Processes of Care for Persons with Dementia, Including Those who Live Alone

**Recommendation 1:** Develop up-to-date, descriptive information about the types of places where persons with dementia live, the number, proportion, and characteristics of persons with dementia who live in each type of place, and their needs for and use of care, services and supports.

**Recommendation 2:** Conduct studies to increase understanding about transitions of persons with dementia from one type of living place to another or one level of care to another in multi-level facilities.

**Recommendation 3:** Develop and evaluate approaches to improve

physical and social environments and processes of dementia care that will be useful across various types of living places, rather than focusing only on one particular type of living place.

*Recommendation 4:* Conduct research to increase understanding about how physical and social environments and processes of care can help to balance autonomy, independence, and choice vs. safety and protection from risk for persons with dementia in all types of living places, including for persons with dementia who live alone.

*Recommendation 5:* Disseminate up-to-date descriptive information about the places where persons with dementia live to relevant groups.

## **10. Financial Burden and Out-of-Pocket Costs to Persons Living with Dementia and their Caregivers**

*Recommendation 1:* Develop comprehensive, descriptive information about dementia-related out-of-pocket costs to persons living with dementia and their caregivers.

*Recommendation 2:* Analyze the relationship of dementia-related out-of-pocket costs to objective and perceived financial burden and examine other factors that may affect that relationship.

*Recommendation 3:* Develop information about the impact of dementia-related out-of-pocket costs and financial burden on persons living with dementia and their caregivers, and identify approaches to address negative effects.

*Recommendation 4:* Develop and evaluate information and educational materials to improve financial decisions and reduce dementia-related out-of-pocket costs and financial burden.

## **11. Ensuring an Adequate and Qualified Workforce to Support Persons with Dementia and their Caregivers**

*Recommendation 1:* Research the impacts of the ever-increasing aging population on the workforce infrastructure and numbers, particularly across regions and workforce type, and develop a solid evidence base for issues around recruitment and retention of workforce for dementia care.

*Recommendation 2:* Examine and include the interdisciplinary team in all phases of research development and implementation, and account for the real-world nature of services to persons living with dementia and their caregivers, such that varied professional and non-professional groups are targeted.

*Recommendation 3:* Define “effective training” for the workforce, including determining what training will increase knowledge and skills for dementia care.

*Recommendation 4:* Determine how existing workforce models can be refined to improve efficiency and cost-effectiveness of dementia care, study impediments to implementation in the existing care system, and develop a better understanding of how these models may affect current infrastructure challenges.

## **12. Technology to Support Persons with Dementia and their Caregivers**

*Recommendation 1:* Develop and evaluate technologies specifically with and for persons living with dementia and their caregivers at various stages of the person’s dementia and across various settings and expand the currently available array of technologies, incorporating novel approaches to increase reach.

*Recommendation 2:* Develop a solid evidence base on the efficacy/effectiveness of technology-based solutions for persons living with

dementia across various functional categories of use and study how technology can assist caregivers to better manage both the care needs of those they care for as well their own needs.

*Recommendation 3:* Conduct research on what types of technology applications are optimal to support various functions for various user groups, determine the impact of the use of technology on providing high quality care to persons living with dementia and their caregivers, and understand how to best integrate these applications within existing models of care.

*Recommendation 4:* Determine whether heterogeneous populations of persons living with dementia and their caregivers are able to access and utilize technology applications, and determine what technology is unavailable and why.

Please take the time to review the Summit report as well as the 2017 National Plan. Understanding the stated goals of the Summit “to identify what we know and what we need to know in order to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and other caregivers” will help us all to intentionally be a larger part of the improvement of quality of care and outcomes across care settings including quality of life and the experience of persons with dementia and their caregivers. Please also visit the Office of The Assistant Secretary for Planning and Evaluation, National Alzheimer’s Research, Care, and Services’ meeting minutes and resources. <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings>.

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Getting on The Same Page continued from page 5

Think about what QAPI stands for and more importantly, what it means. Quality Assurance (QA) looks backward at what happened. Performance Improvement (PI) looks ahead at how to prevent problems in the future. QAPI is the place where we discuss our best analyses, hopes and plans for implementing sustainable improvement. Rather than fretting about surveyors having access to documents, let’s focus our time and resources on equipping staff with the processes, tools, knowledge, and mentorship that support them in caring for the people they serve.

(Endnotes)

1 Jewish Home of Eastern Pennsylvania v. CMS, HHS, 413 Fed. Appx. 532 (3d Cir.2011), cert denied, 132 S.Ct. 837 (2011).

2 Horowitz A. Incident reports, surveys and privilege: Protecting QA material from enforcement action. *iAdvance Senior Care*. 2012. <https://www.iadvanceseniorcare.com/article/incident-reports-surveys-and-privilege>.

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# Dispelling the “Discoverable” Misunderstanding



It's time to dispel a misunderstanding that continues to be perpetuated in nursing homes. Like many of you, I too, was incorrectly taught the meaning of “discoverable” when it comes to incident reports (aka accident and event reports).

To understand the origin of this misunderstanding, refer to the State Operations Manual, the *pre-current revision*, specifically F520, Quality Assessment & Assurance (“QA&A”). This regulation stated,

“Records of the committee meetings

identifying quality deficiencies, by statute, may not be reviewed by surveyors unless the facility chooses to provide them.” What happened in the PALTC industry is that we interpreted that wording to mean anything discussed in the quality meeting (that is, it was on the agenda) was privileged (protected). Many believed that a surveyor could not request copies of documents discussed in the QA&A meeting, which typically included incident reports.

In other words, it was thought that those documents were not *discoverable*.

Let's consider the concept of discoverable. Many staff believed (and still do) that if it was documented in the medical record that an incident report was completed, such documentation made the report discoverable by the surveyor. The surveyor would then have grounds to receive that report whereby it would have otherwise not been available.

Well, that is incorrect. Let's fix this misunderstanding once and for all. This is a difficult issue as it not only requires letting go of a commonly held, but incorrect, belief but also necessitates accepting a reality that is not as welcome.

In a broad sense, discoverable means that a document will have to be allowed to be inspected or copied by another party. (If you desire a more specific definition, please consult an attorney for your state.) Using the situation involving incident reports, discoverable means the surveyor can read, and copy, the report. Discoverability is not dependent on whether or not reference is made to the incident report in the medical record. That is irrelevant. Incident reports are discoverable; they are not privileged.

Let's look at the *current* State Operations Manual as well as the historic legal perspective on this issue.

The revised regulation, F865 Quality Assurance and Performance Improvement Program (PP-922), states, “Incident and accident reports, wound logs, or other reports or records used to track adverse events are not protected from disclosure. Surveyors may request these documents as part of their normal investigation of other areas of concern throughout the survey to support their findings.”

Just to be clear, these documents can be requested and copied whether or not they are referenced in the medical record.

The precedential decision on the issue of privilege (protected from being made public) comes from the Third Circuit Court of Appeals. This case started in a Pennsylvania facility during their survey when they were cited for numerous deficiencies and received an imposition of a civil money penalty. What resulted was a legal battle to determine whether the incident reports were privileged documents. The case was ultimately appealed to the Third Circuit Court of Appeals where it was determined that incident reports are not privileged documents. The facility initially

argued that its incident reports were privileged before a federal Administrative Law Judge (“ALJ”) who agreed with the Centers for Medicare and Medicaid Services (“CMS”) that there is no privilege that attaches to incident reports. The facility then appealed the ALJ's decision to the HHS Departmental Appeals Board (“DAB”), which affirmed the ALJ decision. Unwilling to accept the decisions from the ALJ and DAB, the facility next appealed to the U.S. Court of Appeals for the Third Circuit. In upholding the decisions of the ALJ and the DAB, the Court affirmed that mere incident reports do not enjoy a privilege shielding them from discovery.

Here is an excerpt from the court's precedential decision:<sup>1</sup> (Note: “JHEP” is the acronym the Court used for the Jewish Home for Eastern Pennsylvania.)

After reviewing the record presented, we hold that the documents in question were contemporaneous, routinely generated incident reports that were part of the residents' medical records and were not minutes, internal papers, or conclusions generated by the Quality Assurance Committee. The ALJ found that the Event Reports were given to JHEP's Quality Assurance Committee at the time of the surveys and were not produced by or at the behest of the Quality Assurance Committee. JHEP has presented no evidence to suggest otherwise.

While conducting research for this article, I had the privilege of talking with and learning from Alan C. Horowitz, Esquire, RN. Mr. Horowitz is the attorney that argued that precedential case on behalf of the Centers for Medicare and Medicaid Service. Horowitz says, “The U.S. Court of Appeals for the Third Circuit agreed with my legal argument that there is no privilege for incident reports that would shield them from discovery by surveyors.” Horowitz, who currently represents providers, notes that both the federal statute and implementing regulations draw a distinction between a mere factual recitation of an accident or “incident” on the one hand and the privileged deliberations of a QAPI committee on the other hand.”<sup>2</sup>

In other words, the incident reports are not privileged but the deliberations (discussions) of incidents in the QAPI committee meeting are protected.

So where does that take us? Right back to the importance of documentation that demonstrates excellent critical thinking skills that informs excellent clinical judgment and competent care provided to residents and patients. Incident reports must be completed but exercise appropriate risk management with this task. Review the form used in your facility to ensure that only factual information is documented. After one of my phone conversations with Mr. Horowitz, I reviewed a few different incident report forms and was surprised to find sections that invited the writer to espouse on their opinion of the probable causes of the incident as well as recommendations and referrals made. That information is best suited for discussion in a QAPI meeting, not written on an incident report.

Incident reports should be factual recitations of what occurred; *opinions* are best left for discussions by the QAPI committee. For example, if a resident fell from bed and hit her head, an incident report should not state purely speculative statements such as, “The resident may have been dizzy from her medication.” Mr. Horowitz advises facilities that when it comes to what should be included on an incident report, the mantra is, “Just the facts, ma'am.”

*Continued on page 4*

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