

*Partnerships to Improve Care
and Quality of Life for Persons
with Dementia*

INSTRUCTOR'S MANUAL

CSOMAY Center
for
Gerontological Excellence

**FUNDED BY THE JO HOYT FREEMAN DEMENTIA
EDUCATION AND OUTREACH PERSON CENTERED CARE
INITIATIVE**

CSOMAY CENTER FOR GERONTOLOGICAL EXCELLENCE

COLLEGE OF NURSING

UNIVERSITY OF IOWA

MARIANNE SMITH, PRINCIPAL INVESTIGATOR

Table of Contents

I. TRAINING SERIES BACKGROUND AND OVERVIEW	1
A. OPTIONS FOR USING THE STAFF TRAINING SERIES	2
B. FAMILY INVOLVMENT IN CARE GUIDELINE	3
C. FAMILY-FOCUSED TRAINING SERIES	4
II. USING THE FIC INTERVENTION IN PRACTICE: GENERAL PRINCIPLES	7
III. ADOPTING THE FIC INTERVENTION AND TRAINING IN USUAL CARE	9
A. SETTING TYPE, NEEDS AND RESOURCES	9
B. TYPICAL PATTERNS OF DEMENTIA CARE	9
C. FAMILY-INVOLVEMENT IN DEMENTIA CARE	9
D. STAFF INVOLVEMENT IN DEMENTIA CARE.....	10
E. DEMENTIA TRAINING FOR STAFF	11
F. PLANNING A QUALITY IMPROVEMENT PROCESS	12
MODULE 1: INTRODUCTION & OVERVIEW.....	15
MODULE 2: UNDERSTANDING CHANGING NEEDS OF PERSONS WITH DEMENTIA	16
MODULE 3: ROLE CHANGES FOR FAMILY MEMBERS	18
MODULE 4: INTERACTING WITH FAMILY MEMBERS	19
MODULE 5: STAFF-FAMILY PARTNERSHIPS: FIRST STEPS.....	20
MODULE 6: STAFF-FAMILY PARTNERSHIPS: NEGOTIATION IN DEMENTIA CARE	22
MODULE 7: FAMILY-STAFF PARTNERSHIPS: FORMING A PARTNERSHIP AGREEMENT.....	24
MODULE 8: PERSON-CENTERED CARE: AN OVERVIEW	25
MODULE 9: STAYING PERSON-CENTERED: OPPORTUNITIES AND METHODS	26
MODULE 10: KNOWING THE PERSON WITH DEMENTIA: <i>LET ME INTRODUCE YOU TO</i>	28
MODULE 11: GOAL-DIRECTED CARE: IDENTIFYING AND USING VALUES TO DIRECT DECISIONS	30
MODULE 12: COMFORT CARE IN DEMENTIA CARE: FAMILY INVOLVEMENT IN ADVANCED PLANNING.....	32

V. SIGNING INTO THE IOWA GERIATRIC EDUCATION CENTER..... 34

VI. ACCESSING THE FAMILY INVOLVEMENT IN CARE TRAINING SERIES 40

APPENDIX 1: SPECIAL THANKS TO OUR FUNDING SOURCE..... 44

APPENDIX 2: SPECIAL THANKS TO LEADERS AND CONTRIBUTORS 45

I. TRAINING SERIES BACKGROUND AND OVERVIEW

The modules in the staff training series, *Partnerships to Improve Care and Quality of Life for Persons with Dementia*, are built on the ideas and practices that were evaluated in the original research study which was called *Nursing Intervention for Alzheimer's: Family Role Trials* that was designed to implement and evaluate family and staff working as partners in dementia care. The successful approaches used in the study were later developed as an evidence-based practice, *Family Involvement in Care (FIC) for Persons with Dementia Evidence-Based Guideline*© that is published by the University of Iowa College of Nursing Barbara and Richard Csomay Center for Gerontological Excellence. [<https://www.iowanursingguidelines.com/product-p/873.htm>]

Content in the *Partnerships to Improve Care* training series for staff caregivers overlaps with content in a companion training program that is designed for family members. The companion program is called *Advancing Care Partnerships: Family Involvement in Care*. The two training series are meant to help BOTH staff and family members gain skills to work as partners in providing high quality dementia care. The partnership approach outlined in each of the two training series, one for staff and the other for family, is based on the *Family Involvement in Care* (FIC) intervention. Throughout this manual we may use “partnerships” and FIC intervention or FIC model interchangeably.

The goals of this *Instructors Manual* are to help learners and leaders:

- Best use the staff training series: for individual learning or review of ideas; as a group training program; and/or as the basis for implementing the Family Involvement in Care intervention in a practice setting.
- Understand how the staff training series builds on the EBP Guideline, and how the two may be used together if desired.
- Recognize similarities and differences between the staff and family training series, and how the family training may be used to support using the FIC intervention in practice settings.
- Identify strategies to implement the FIC intervention in practice.
- Use supportive handouts, training materials, videos, and other supportive materials to facilitate learning (training) and use in practice.

In summary, this manual is provided to help users tailor the *Partnerships to Improve Care* staff training series to best fit the needs and goals of the care setting and individual users. Let's start by reviewing some the options for using the staff training series.

A. OPTIONS FOR USING THE STAFF TRAINING SERIES

There are several options for using the online *Partnerships in Care* staff training modules and materials, as briefly described in the sections below. There is no one “best” way to use the training, and options can be used individually or together. That said, adopting the FIC intervention as part of “usual care” in a setting that provides dementia services and care is the most likely to achieve the benefits outlined in the training series: improved staff satisfaction, improved family satisfaction, and higher quality care for persons with dementia.

Individual Learning. The training series can be easily accessed online by individual staff providers (and others) as a “self-improvement” or professional development activity. The training helps individuals gain new knowledge and skills about the partnership model and FIC intervention. The ideas support quality caregiving practices and interactions with family members WITHOUT necessarily adopting the FIC intervention as a routine part of care in a specific care setting. Leaders in care settings can also direct staff to take specific modules as an individual learning activity to help them gain new skills, or as “booster training” to remind them to use skills they already possess. The modules are short – about 15 minutes each – to allow easy on-the-job access.

Group Learning. Training small groups of staff caregivers at one time is often helpful to gain a shared view that is then used in practice. Group learning is best directed by a staff leader who organizes the topics in a timeline, engages learners to participate, arranges technical aspects so the online training can be viewed, and assures that supportive handouts and materials are available for discussion during the group training session. Because modules are short, they can be used in combination, two or three at a time, if that best fits the needs of the setting. However, how many modules are combined, and how training sessions are organized are decisions that staff leaders can make to fit the individualized needs of the setting. The materials in this manual provide a module-by-module outline which include supportive videos, handouts, and companion family training materials that best “fit” each training topic.

Using Training in Practice. We believe the best use of the training is to help staff gain skills to use the FIC intervention in practice settings. This requires some additional planning on the part of key leaders related to implementing the ideas about (a) engaging select family members in discussion, (b) assessing family needs, and also the needs of the person with dementia, (c) holding a planning meeting with family and staff to develop a partnership agreement, and (d) following up with staff and family to best assure the targeted outcomes of care. However, the long-term benefits of using the partnership approach in daily practice can have remarkable outcomes related to staff and family satisfaction and quality of care for persons with dementia. Those who are interested in the implementation approach are asked to review Section III that provides guidance about using a quality improvement approach to adopt the FIC model.

Using Complimentary Family-Focused Training. A main feature of the FIC model is that high quality dementia care relies on BOTH staff and family having some basic skills. The FIC model outlines important content for family members, just as it does for staff caregivers. The

companion family-focused training, *Family Involvement in Care: Advancing Care Partnerships*, provides an easy-to-access and use format for family members to gain skills in dementia care. The content in the series addresses the “family education” part of the FIC model, as outlined in the *FIC Evidenced-Base Guideline*. We believe that STAFF benefit from understanding the content that families are provided, particularly in settings where the goal is to adopt the FIC model as part of the ongoing standard of practice. See Section C for more information the family-focused training series.

B. FAMILY INVOLVMENT IN CARE GUIDELINE

The *Partnerships to Improve Care* training series is designed to complement the *Family Involvement in Care (FIC) for Persons with Dementia Evidence-Based Guideline*©. At the same time, there are some differences that are important to understand when planning to use the training series.

The *Family Involvement in Care Guideline* is clearly focused on implementing the FIC intervention in practice settings. The five main elements of the FIC intervention are described and supported with materials to facilitate implementation. As a reminder, those elements are:

- 1) Assessment of families (family caregiver(s) and the person(s) with dementia);
- 2) Orientation of an identified family member(s) to the setting;
- 3) Education of staff and family member(s) for involvement in care;
- 4) Negotiation and formation of a partnership agreement; and
- 5) Follow-up with family member(s), staff evaluation of outcomes, and renegotiation of the partnership agreement.

The *Guideline* includes detailed forms related to using the FIC intervention in daily practice. Most of these have been pared down for discussion in the training series, and modified to help a broad group of dementia providers and staff members use the ideas in practice. The *Guideline* contains some additional information that the training series does not include, such as:

- Longer versions of the family assessment form, and also assessment forms for evaluating the functional level, cognitive level, and interests in pleasurable activities of the person with dementia;
- Nursing classification diagnoses, interventions, and outcomes that may be used to evaluate care in practice settings;
- Forms to evaluate adoption of the FIC intervention in practice, such as scale that rates the frequency and type of use, and another that evaluates staff knowledge; and
- References about the evidence that supports the practice of involving family in dementia care, and each of the key components of the FIC intervention.

The *Partnerships to Improve Care* training series for staff includes key information that the FIC Guideline recommends for staff and family training. Remember, staff and family education for involvement in care is one of the five elements of the intervention. The *Partnerships in Care* series directly follows the content for training staff that is recommended by the FIC Guideline: (1) Care of Residents with Dementia and the Role of Family Caregivers; (2) Family Involvement in Care Intervention, and (3) Family-Staff Partnerships for Dementia Care. The learning objectives for these three staff training programs are addressed in the first seven modules of the *Partnerships* training series. Additional materials in the *Partnerships to Improve Care* series are focused on providing person-centered care (3 modules) and changing goals of care as dementia progresses (2 modules). Of importance, the staff training series includes references to the family-focused companion training.

C. FAMILY-FOCUSED TRAINING SERIES

Providers who wish to adopt the partnership model as part of usual care in their setting will want to use selected training modules from the companion training series, *Family Involvement in Care: Advancing Care Partnerships*, which is designed to educate family member about the FIC intervention. Family education goes hand-in-hand with staff education, so we recommend that leaders and key staff briefly review the main topics and ideas in family training. We have worked to assure that main “messages” about changing roles, communication between staff and family, and the process of developing a partnership are clear and consistent in each series.

The staff-focused series and companion family-focused training series, address similar FIC-related topics but in a different order. One important overall difference is that the family-focused training was developed using software called Prezi, and the staff-focused training was developed using software called PowerPoint. That means that the two will look quite different.

The other important difference is that the staff training contains more supportive handouts and instruction (like this manual) to promote using the FIC intervention in practice settings. In contrast, the family-focused training is designed to help family caregivers (a) be knowledgeable about the FIC intervention and partnership approaches, and (b) gain skills to advocate for being partners in care with diverse care providers with whom they interact -- in clinics, home care, residential settings, day care, and other services.

The family-focused training is available at the Iowa Geriatric Education Center (IGEC) website available for free. You can access the training at <https://igec.uiowa.edu/fic>. The IGEC requires that learners provide basic background information that is required for reports to their federal funding agency. This is a one-time registration in which users select a “user name” and a password that allows easy log-in in all subsequent visits to the site. Please see Section V of this manual for instructions and screen shots to help *Partnerships to Improve Care* users easily access the IGEC-based training.

As described on the IGEC website:

Family Involvement in Dementia Care empowers family members to establish partnerships with formal care providers in order to provide coordinated, person-centered care for individuals with dementia. Educational videos, interviews, hand-outs and break-out discussions teach family members to work as partners in care with providers in both community and residential care settings. The ten-part series covers topics such as communicating with providers, negotiating on behalf of your loved one, how to ask difficult questions, managing medications, and more. All are designed to help family members better and more comfortably represent the needs and preferences of their loved ones. The focus is on the delivery of person-centered care, which involves knowing, respecting, and valuing the person's lifelong characteristics and abilities.
<https://igec.uiowa.edu/fic>

Recommendations include using the 10-part family focused training program in sequence since each topic build on earlier ones. Topics and brief descriptions include:

FIC Overview: Review the background of the training series and importance of family involvement in dementia care.

Talking to Providers: Develop skills to prepare yourself for interactions with health care providers such as asking better questions, getting the information you need, and clearly explaining your concerns can reduce stress and improve care.

Don't Be Shy: Gain skills on being assertive (vs aggressive or passive) when speaking with health care providers to help you ask difficult questions, offer information, speak up for yourself and your needs and to stay focused on issues most important to you.

Finding the Best Solutions: Develop skills to engage in a “back and forth” process with providers to help family caregivers find the best solutions for care and treatments for their loved ones.

Partnerships in Caring: Utilize skills already learned in previous presentations to develop a partnership approach to caregiving with the health care provider. Partnership relies on good communication, working as a team, and staying focused on the quality of life and outcomes for the person with dementia.

Understanding Behaviors: Learn to look at behavior as a form of communication, take time to assess the person and situation to recognize unmet needs, environmental contributors and triggers that may impact a behavioral response from your loved one.

Responding to Behaviors: Building on the previous presentation, learn to adjust approaches to care based on your loved one's preferences and abilities to reduce challenging behaviors and promote their involvement in their own care.

Medications and Treatments: Develop skills to talk with providers about medication and treatment use, adverse side effects, and other options to make better informed decisions.

Changing Care Settings: Gain skills to ease the stress of transitions between levels of care, such as home to assisted living, nursing home, or hospital; assisted living to nursing home, other transitions.

Changing Goals of Care: Learn to adjust goals of care based on the changing needs of your loved one with dementia; consider needs and issues related to the person's stage of dementia, function, and quality of life.

Comfort Care: Review similarities and differences between palliative and hospice care in the context of progressive dementia, changing goals of care, and the increasing importance of the person being comfortable vs. lengthening life in late stage dementia.

II. USING THE FIC INTERVENTION IN PRACTICE: GENERAL PRINCIPLES

The Partnerships to Improve Care training series is designed to support adoption of the FIC Intervention in practice. Adopting ANY evidence-based practice requires advance planning to assure the practice “fits” organizational needs, and is sustained over time. This section reviews some general principles and ideas for putting the FIC intervention into use. To help keep this simple, we use bulleted points that review key issues. In Section III, we outline specific questions and issues that should be addressed in order to successfully implement the FIC intervention and associated training in practice settings.

- **What type of practice setting is being considered for adopting the FIC intervention?** We strongly believe that nearly ANY setting that provides dementia-related services, but difference in staffing, the type and frequency of contact with family caregivers, and other issue will make a big difference in how the intervention is best used.
- **Which key leaders will help plan the training AND use in practice?** Successful adoption of ANY evidence-based practice, including the FIC intervention, relies on leadership “buy-in” and engagement.
- **Who and how will family members be engaged as partners in care?** This generally involves
 - ✓ Having discussions with family members about their interest in being partners,
 - ✓ Assessing family needs and interests (using training forms/materials),
 - ✓ Scheduling planning and follow-up meetings that involve both staff and family, and
 - ✓ Selecting and using the companion training modules with family members.

We highly recommend using a rapid cycle quality improvement (RCQI) approach. That is, try the process with one or two families to see how it goes, work out any barriers or problems, and then repeat the process on a small scale until it becomes comfortable. Using RCQI can help staff from feeling overwhelmed by their new responsibilities and expectations, and help resolve any unanticipated issues.

- **Who and how will family training be conducted?** The online training offered through the IGEC, *Family Involvement in Care: Advancing Care Partnerships*, provides an excellent basis for completing family education that is part of the FIC Intervention. We recommend the following:
 - ✓ The first six training modules in the family series be taught as part of the Orientation of Family step in the intervention.
 - ✓ Key leaders and staff caregivers should also take the family-focused training to assure they can answer questions and support family learning.

- ✓ Family should be helped to navigate the online training, either by taking the training onsite at your organization, or by offering help family members get started with logging on and way-finding to promote being successful at home.
- ✓ The family-focused training has also been successfully used in residential and nursing home family support groups and dementia support groups, which offers another option for educating families.
- **Who and how will staff training be conducted?** As outlined in the earlier section, there are many options for training individuals and groups. When planning to implement the FIC intervention as part of the care and treatment your setting provides, we highly recommend that:
 - ✓ The first seven training modules be taught before implementing the intervention. This content provides the essential skills that staff need, as outlined in the *FCI Guideline*.
 - ✓ The three modules on Person-Centered Care be taught as a sequence. This content is highly supportive of the intervention, and can be taught along with the first seven modules or at a later time.
 - ✓ The two modules on goal-directed and the hospice approach to care be taught last. This content is perhaps best used in conjunction with real case planning and discussion (e.g., care of a person who is being treated or cared for by staff in your setting). These two modules can also be taught as part of the overall training sequence since they support ideas related to changing needs of families and persons with dementia, and relate to the need to renegotiate partnership agreements.

The next section provide specific guidance for adopting the FIC intervention as the standard of care for daily practice.

III. ADOPTING THE FIC INTERVENTION AND TRAINING IN USUAL CARE

The following information and guidance is designed to help settings and services that would like to adopt the FIC model as the standard of care in their practice setting. While there is no one “right” or “wrong” approach to adopting an evidenced-based practice for long-term use, there are some standard considerations that we have tailored to using the FIC model. Given that practice settings are considerably different from one another – even within setting “types” – we offer broad questions and ideas to stimulate conversations among senior leaders who are planning the changes. The ideas are clearly NOT exhaustive, but are intended to stimulate thought to guide planning.

A. SETTING TYPE, NEEDS AND RESOURCES

An important starting point is to consider your setting, and the unique needs, resources, and opportunities that may exist related to adopting the FIC intervention. The questions are designed to help providers and services think about the demand for partnership-based care, and also ways to implement programming on a small basis to best assure success (e.g., rapid cycle quality improvement model, which we highly recommend).

B. TYPICAL PATTERNS OF DEMENTIA CARE

We suggest that you start by thinking about demand or volume of dementia care services you provide. This may vary from setting to setting and by programs within settings (e.g., dementia care unit, dementia care in assisted living, dementia care in nursing home all on the same senior living campus). The goal is to understand the best starting point for adopting the FIC intervention.

- How many persons with dementia do you serve overall?
- Do you have more than one program that service persons with dementia? If so, consider each separately in planning.
- How often do persons with dementia move through your service/care setting? That is, what are average patterns of admissions and discharges?
- About how long do those with dementia remain in your care?

Main Point → Services that tend to provide dementia care over longer periods of time are often the best target for implementing the FIC model.

C. FAMILY-INVOLVEMENT IN DEMENTIA CARE

Next, think about the number of persons with dementia who have family members who are involved and accessible, and thus are candidates for the FIC intervention and partnership in caring approach. As you do this, also think about any current practices related to family involvement that you are already using.

- How many persons with dementia typically have families who are involved in services/care?

- ✓ Nearby/accessible? (are physically present)
- ✓ Distance caregivers (accessible, but don't visit/accompany to appointments)
- What are the biggest challenges you face with family involvement?
- When are challenges most often encountered? In what type of situation?
- Who is most often involved in resolving problems or conflicts?

Main Point → Thinking about the most pressing needs related to family involvement in care can help guide decisions about how many should be involved in a QI project, and also under what circumstances. The main choices are to implement the FIC model with new admissions, OR target the process to selected families who may benefit from the approach (more on that below).

- What policies (if any) do you have for family involvement in dementia care?
 - ✓ Do you routinely assess family perceptions about the person's care needs? (Admission, other)
 - ✓ Do you routinely assess family role strain or caregiver stress?
 - ✓ Do you assess family member's knowledge of dementia?
 - ✓ Do you engage family in assessments and discussion of their relative's remaining abilities as well as limitations and behavioral symptoms?
 - ✓ Do you provide any dementia or caregiver-related training to families?
 - ✓ Are family members routinely part of planning care and services? If so, how?
 - ✓ Do family members routinely provide care (as outlined in the service/care plan?)
 - ✓ Does your setting/service provide any volunteer roles for families?

Main Point → Building on existing strengths or resources (OR using past negative experiences) to guide practice changes can help ease adoption. Developing a routine approach to assessing family needs along with the needs of their relative with dementia provides an important foundation for discussion, interaction, and partnership-building.

D. STAFF INVOLVEMENT IN DEMENTIA CARE

The type, number, educational level, and dementia-specific training of staff who provided dementia care all make a difference in developing plans. The direct care workforce is a logical target because they are routinely involved in caring for persons with dementia AND interacting with families. However, the supervisory and leadership team qualities are just as important to consider when implementing practice change. As you consider questions about staff, consider how you will (1) engage staff in the process of providing partnership-focused care, (2) train the right staff have the right skills to implement the FIC model successfully, and (3) develop policies about both family involvement and possible conflict management with family members.

- What is the overall composition of staff who are directly involved providing dementia care, and interacting with families?
 - ✓ Nurse Managers?
 - ✓ Nurses?
 - ✓ Social Workers?
 - ✓ Nursing assistant/aids?
 - ✓ Universal workers?
 - ✓ Activity staff?
 - ✓ Related personnel (therapy, dietary, housekeeping, other)
- Do you have a “core” staff that are stable employees? (E.g., engaged, not likely to leave; good candidates for training/involvement in practice change)
- Do you have “natural leaders” that are willing/interested in quality improvement? If so, how might they be involved?

Main Point → The FIC model places considerable importance on the role of ALL workers, particularly those who provide direct care to persons with dementia and are likely to interact with family members related to the quality of care and services. Thoughtful consideration of the strongest, most natural leaders is key to building a FIC team during the QI project, a team that in turn will help spread use of the practice throughout the setting/service.

E. DEMENTIA TRAINING FOR STAFF

- What are your current policies for providing dementia training?
- Does your dementia training include content about family needs?
- What is your current preferred format for providing staff training? E.g., online, group in person, just-in-time 1:1?
- What barriers exist to implementing the required training?
- What opportunities exist to support/extend the required training?
- What approaches do you use to support use of dementia care practices taught in training?

Main Point → Building on current strengths and practices will help support ongoing use of the FIC model and staff training. At the same time, recognize deficits in dementia training or support staff to use recommended approaches in daily care.

F. PLANNING A QUALITY IMPROVEMENT PROCESS

Additional more specific considerations are essential to planning a quality improvement (QI) project that implements the FIC Intervention on a small basis. The QI approach identifies barriers or problems and resolves them before using the process throughout the organization or service. The goal is to think carefully about what is involved in implementing the process, and how to make a plan that outlines both key leaders for activities and the timeline for moving the project ahead.

- Which service or program will implement the FIC model first?
- How many family members/persons with dementia do you plan to engage in your “trial”? (e.g., small quality improvement project that focuses on solving any unexpected barriers before adopting in the overall setting or service)
 - ✓ What process will you use to engage family? E.g., At admission? Selected from those currently being served?
 - ✓ If a selection of current families, what criteria will be used?
 - ✓ Are there any potential “pitfalls” to overcome by selecting some but not all? If so, how can that be best addressed?
- Which key leaders will be responsible for implementing and evaluating the FIC model QI project? E.g., shared responsibility is best.
- Which key leaders will perform which part of **family engagement/involvement**?
 - ✓ Orienting family to the setting/service: Discussing the partnership model; your setting’s philosophy of dementia care; your goal for their input
 - ✓ Family assessment: History, characteristics, role strain
 - ✓ Family perception of person’s needs: Views of strengths, problems, best approaches
 - ✓ Family training: The first six modules from *Advancing Care Partnerships: Family Involvement in Care* are highly recommended; the remaining four are optional.
 - What training format will be used with family? Online at home? On site at your organization?
 - Individual? Or in a support group or other group format?
 - If group, who will schedule, facilitate?
 - If online, who will assist families to be successful? Assure they complete required modules?

- Which key leader will lead/oversee **staff engagement/involvement**?
 - ✓ Staff selection: Which staff will be involved in the QI project? Remember that staff who provide care to the person with dementia whose family member is participating in the QI project should be involved.
 - ✓ Staff training: The first seven modules of the *Partnerships to Improve Care* series are essential. The additional 5 modules are highly recommended, but optional.
 - What training format will be used? Online or group?
 - If group, who will schedule, facilitate?
 - If online, who will assure staff complete the required modules?
 - What timeline do you plan for staff training?
- Which key leaders will lead/oversee the **negotiated Partnership Agreement planning meeting**?
 - ✓ Will this planning meeting be part of another care or service planning meeting? Or held as a separate meeting?
 - ✓ How will you best assure that representative staff (trained as part of the project) can attend?
 - ✓ How will you explain the meeting to the designated family member?
 - ✓ Will other family be invited to the meeting? How can you best assure the study participant is the main spokesperson during the meeting?
 - ✓ What information or FIC intervention steps will need to be done before the meeting?
 - ✓ How will you approach re-evaluation and re-negotiation of the Partnership Agreement?
 - ✓ Who are the key contacts if problems or issues occur before the next scheduled meeting?
 - Who will family members go to?
 - Which key leader will address new problems with family?

In summary, there are lots of issues to consider before implementing ANY practice change. The goal is to start small and work out problems as they are encountered. This approach helps reduce the sense of feeling being overwhelmed that too often occurs in system-wide changes. Planning the process in advance helps to identify issues that might otherwise be overlooked – things as simple as conflicts in scheduling rooms for training meetings, or as complicated as how many and what type of staff to include in the first cycle of training. Overall, however, the process increases the sense of being successful that fosters use in practice.

One of the most successful models for rapid cycle quality improvement is called Plan-Do-Study-Act, or PDSA, which is described online at: <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/QAPI/downloads/PDSACycledebedits.pdf>

IV. MODULE SPECIFIC INFORMATION FOR GROUP TRAINING

We provide additional information and guidance about each of the 12 training modules in the pages that follow. The goal is to provide additional information and guidance to key leaders who may conduct group training programs with staff. Each module contains information that may be used for advertising or securing continuing education credits if desired, including:

1. Statement of Purpose
2. Learning Objective(s)
3. Notes for Instructors related to the rationale for the content and use in practice
4. Breakout Discussions/Moments that are part of the module that are designed to encourage application of ideas in practice
5. Handouts that support the content in the module

MODULE 1: INTRODUCTION & OVERVIEW

Purpose: This program provides a brief introduction to the *Partnerships to Improve Care* staff training series and its relationship to (a) research that evaluated the Family Involvement in Care Intervention, (b) the *Family Involvement in Care (FIC) for Persons with Dementia Evidence-Based Guideline*©, and (c) the companion training for families, *Family Involvement in Care: Advancing Care Partnerships*. The main steps in the Family Involvement in Care Intervention and the training series are briefly reviewed.

Learning Objectives:

- Discuss relationship of the Partnerships in Care training to an earlier research study and resulting evidence-based guide.
- Identify benefits of family-staff partnerships.
- Review the topics for the training series.

Notes for Instructors: This introductory training module briefly introduces the content in the series, with an emphasis on both WHY it is important, and how the content is linked to both research and the evidenced-based guide about the FIC intervention. An important starting point for leaders and other instructors is to understand that the series is not designed to replace longer dementia training programs that spend more time discussing common issues and problems. Instead, it is intended to complement other training, and set the stage to help staff understand WHY family members may not react or think like they do. The aim is to sensitize staff to the challenges families face in caring for a loved one with dementia, and underscore how family's lack of knowledge about dementia may create stress for them and staff.

We highly recommend that the modules in the series be used in sequence since one topic provides important information for the next. This first module can be used as (a) the starting point for discussion among staff leaders about the series and how it may be best used in the organization or service; (b) a single program viewed on-line or in a group; or (c) in combination with additional modules in a longer staff development program.

Breakout Discussion/Moment: None for this module.

Handouts:

- Steps in the Family Involvement in Care Intervention

Links:

- Family focused training <https://igec.uiowa.edu/fic>
- FIC Guideline <http://www.iowanursingguidelines.com/>

MODULE 2: UNDERSTANDING CHANGING NEEDS OF PERSONS WITH DEMENTIA

Purpose: The slow loss of abilities in dementia can make it hard to know how to best support independence and involvement in both daily self-care and meaningful activities for those with dementia. This program briefly reviews common types of dementia and how symptoms may be “confusing” to family and caregivers alike. Common losses with the four main stages of dementia are reviewed, and a model that helps explain problem behaviors in dementia is introduced.

Learning Objectives:

- Identify different types of dementia besides Alzheimer’s disease
- List common challenges in the early, middle and late stages of dementia
- Describe how the Need Driven model of dementia care can help explain challenging behaviors

Notes for Instructors: This module provides basic information about dementia that can make care both challenging and confusing to staff and family caregivers. Key ideas covered in this module include: (a) how different types of dementia can have different characteristics and challenging behaviors, (b) how behaviors change over time as the dementia progresses, and (c) how these changes in function, self-care, and interest in activities can be confusing for staff and family. That is, no two people with dementia will be alike, and the person’s abilities will change over time. They are not being stubborn or disagreeable, they simply can’t do what they were able to do earlier! The other focus is using the Need-Driven Dementia-Compromised Behavior (NDB) model to help explain psychological and behavioral symptoms. The NDB model focuses on the interaction between reasonably stable characteristics, like longstanding habits and personality, the type and stage of dementia, and other medical problems, AND fluctuating factors in the environment that staff and family may influence.

This program lays the foundation for reviewing changing roles for family members, and how that can contribute to stress and distressing emotional reactions.

Breakout Discussion/Moment: This module includes a situational discussion question.

Instructions on the PowerPoint slide direct participants to “Imagine you are leading an activity when one resident becomes upset-crying and yelling for others to get away from her. What might be possible triggers and how would you best approach / provide support?”

The image shown depicts that it is the holiday season and it is snowing outside. Some possible triggers could include:

- The time of year / holiday season if the person with dementia had a traumatic event occur
- Level of noise due to the activity could cause increased confusion / agitation

- Movement causing acute pain
- Other person-centered reactions

Interventions may include asking the resident if they would like to go to a quieter location to talk. Be sure to approach the resident from the front and get to their eye level.

The goal of this breakout discussion is to have the learners use the “Need-Driven Behavior Model” to assess possible individual and environmental factors that could be contributing to the person’s experience and reaction to the activity. Facilitate the discussion as needed and then press play to continue the presentation.

Handouts:

- Stages of dementia
- Need-Driven Dementia-Compromised Behavior or NDB model

MODULE 3: ROLE CHANGES FOR FAMILY MEMBERS

Purpose: Being a family caregiver for a person with dementia causes a wide variety changes and challenges. These role changes can be very stressful, and may lead to problems with staff care providers. Understanding common issues can help staff respond to anger, frustration, blame or other emotions, and help to solve the “real” problem. Best approaches for responding to upset family members are introduced.

Learning Objectives:

- Discuss changes that may cause stress for family caregivers
- Consider how stress contributes to interactions with staff
- Review approaches that may help ease tension

Notes for Instructors: The overall aim of this module to help “sensitize” staff to the many challenges that family members of persons with dementia face, including both caregiving stress and stress that comes from other aspects of life. The main point is that staff caregivers may wrongfully think that the “stress is over” once the person with dementia is receiving services, or living in a supported setting. They may underestimate what factors are “operating in the background” that impact family behavior, and thus be caught off guard by emotional responses that are not directly related to factors in the immediate care situation or setting. Helping staff caregivers think about family as people who often have many other concerns and worries BESIDES their relative with dementia can help “normalize” interactions that may otherwise become tense. We also think that ALL staff need to develop basic skills in responding to emotionally tense situation. We highly recommend that leaders emphasize that the communication skills taught in this and the next module are not just for interacting with families! These skills have direct application to interacting with other staff in the work place, AND to interacting with friends and family at home.

Breakout Discussion/Moment: There is a short video clip of a caregiver (Sarah) discussing the emotions that family caregivers experience. Please pause the presentation to allow the learners to discuss how they have provided support and empathy to family members that express guilt and/or grief. Facilitate the discussion as needed. Possible examples include allowing family time to express their feelings, supporting family members to take time away for themselves, offering supportive resources such as a support group, and inviting family to be involved in their loved one’s daily life.

Handouts:

- None for this module.

MODULE 4: INTERACTING WITH FAMILY MEMBERS

Purpose: Listening to strong emotions without “reacting” in a negative way is challenging. At the same time, arguing rarely solves problems. This program reviews ways to listen with the intent of understanding the other person’s “real” problem, staying calm, and knowing when to direct the issue to a supervisor.

Learning Objectives:

- Discuss communication techniques and approaches
- Identify “pitfalls” and ways to avoid them
- Review strategies to help families find solutions to emotional distress

Notes for Instructors: This presentation builds on the content in Module 3 by offering more detail about communication approaches that may be used in tense emotional situations. As before, we believe all staff caregivers benefit from developing basic skills and understanding of how to best respond to emotionally distressed person – family, residents, other staff, and their own social network. We recognize that these skills are not learned in one short training program but must be practiced over time. To that end, we highly encourage leaders to role model these approaches, engage staff in practice sessions, and also offer “just in time” training when staff are observed using less-than-optimal approaches (e.g. taking staff aside and asking them to think about another way to respond and briefly discussing options in a non-punitive way). Listening with the intent of understand the “real issue” and using “I” statements, in particular, are important “life skills” that can help staff manage many situations. We highly recommend that leaders emphasize that the training applies to life in general, and can help staff as individuals – not just in care of persons with dementia and family caregivers.

Breakout Discussion/Moment: The breakout is a situational discussion. As described in the PowerPoint slide, “Susan visits her mom one evening after work and finds her in bed sleeping. Susan is upset because she has addressed her concern with her mom going to sleep too early in service plan meetings. Imagine you are a resident assistant and you see Susan coming into the dining room to confront someone about her frustration. How would you address the situation?”

Possible ways to handle the situation may include meeting Susan and asking if you can discuss her concern in a quieter location. Listen to her concern without interrupting or judging, check your understanding of her concern and assist to find a solution. That may be providing an explanation such as her mom was not feeling well or did not rest earlier in the day and had an early supper.

Handouts: None for this module

MODULE 5: STAFF-FAMILY PARTNERSHIPS: FIRST STEPS

Purpose: Developing a staff-family partnership related to caring for a person with dementia has many benefits – for family, staff, and most importantly, the person with dementia. This program provides a brief overview about staff-family partnerships, and benefits to everyone involved.

Learning Objectives:

- Review main elements of the Family Involvement in Care (FIC) intervention
- Review steps to implement the intervention with family

Notes for Instructors: This module is the first of three that discusses the main steps in the Family Involvement in Care (FIC) Intervention. We strongly encourage leaders to review all three modules before teaching this sequence to assure you are familiar with the “big picture” of content and how it is used in practice. The first module discusses the main components of the FIC Intervention, and offers supportive handouts (listed below) that are designed to help implement the model in daily care. We highly recommend that users print the handouts before viewing the module so they can review ideas as they are discussed in the presentation. We would like to call attention to some aspects of the training that should likely be discussed or reinforced as part of the training and also in practice. On slide 3, we note

One important thing to keep in mind as we talk about the intervention and its use is that different types of staff play different roles in CARE. Some of the review of how the Intervention works may feel like “that’s not my job, so why do I care?” The answer is this: To be a strong team member in providing care, ALL staff need to have the “Big Picture” of what contributes to high quality care. You may not be the person who actually ORIENTS family to your setting or the partnership approach, but understanding how that works is important to being a team member!

We ask that organizational leaders work to help EACH staff member to feel valued as a member of the family-staff partnership process and team. We recommend that leaders discuss how team members in different roles, such as nurses, CNAs, dietary workers and even housekeeping, can work together to provide the best care possible to the person with dementia AND their family members. This will be individualized based on the care setting, but might include examples such as dietary staff supporting helping family involvement in meals, housekeeping supporting family to rearrange items in the person’s room, or nursing assistants asking family about longstanding habits or interests. The goal is help all staff understand how they can help AND feel valued for their contributions.

Another key point is outlined on Slide 4:

The role of the family becomes blurred, and in settings like residential or nursing home care, family often feel like “visitors.” Without having a clear plan in hand, families may feel “dismissed” or even unwelcome.

We ask that organizational leaders think carefully about this issue, and how the “culture of care” in your setting may help deter this experience for family. Organizational leaders have many opportunities to role positive behaviors related to welcoming and engaging families in care, and can reinforce approaches through discussion with daily care providers.

The third main point is that this module covers a lot of new ideas related to team work and family involvement that will take some time to “digest.” By that, we understand that using the information in a practice setting takes considerable thought, discussion, and planning. We highly recommend that leaders review Sections II and III in this manual for additional ideas about using the FIC Intervention in your practice area.

A final observation about this module is that it is slightly longer than most of the others, particularly when time is taken to review the handouts and discuss the ideas in group training. At the same time, the next module, Negotiation in Dementia Care, is slightly shorter. If the three modules about Family-Staff Partnerships are taught as a single group training program, the time should balance out.

Breakout Discussion/Moment: None for this module.

Handouts:

- Orienting Families to Being Partners in Care
- Questions and Ideas for Family Members
- Assessment Inventory
- Family-Staff Partnership Agreement
- Activity Options: Simple Pleasures

MODULE 6:

STAFF-FAMILY PARTNERSHIPS: NEGOTIATION IN DEMENTIA CARE

Purpose: Partnerships are based on the unique needs of the family, person with dementia, and caregiving situation/setting. This program builds on content in Module 5 but describing the process of negotiation that is the focus of Step 3 in the Family Involvement in Care (FIC) Intervention. Ideas underlying the FIC Intervention are briefly reviewed, and how working as “partners” with family can be a big change for staff caregiver. Coming to a mutually satisfying agreement between staff and family may be tense at times, as differing views on goals of care and needed activities are discussed. In turn, this program also reviews basic ideas about conflict resolution.

Learning Objectives:

- Review principles of negotiation
- Describe conflict resolution and how it works in negotiation

Notes for Instructors: The content in this module is based on the original training provided to staff in the research study that tested the FIC Intervention. The idea of “negotiation” may not be familiar to staff caregivers working in health care settings. In turn, other language and examples are needed to illustrate what is meant, and how negotiation can be used in dementia care. We ask that you focus on the aspects of negotiation being a “give and take” process that leads to a mutually satisfying agreement. As this module emphasizes, cooperative negotiation is a skill that is **LEARNED** and required practice. Since organizational leaders will likely lead the negotiation meeting that is part of the FIC intervention, they must understand and use the principles so that other staff can follow their example.

Although we have included the example of “Mrs. Smith” (Slides 10-11), discussing “real-life” examples that your staff face is an even stronger approach. The ideas on Slide 12, in particular, may be used to review how changing abilities in a person with dementia have led to different viewpoints (and possible conflict) about the best approach to use in daily care.

Breakout Discussion/Moment: The breakout moment in this module is a situational discussion regarding a family member who is upset about her husband’s appearance (staff are parting his hair incorrectly). Staff feel that she is being overly critical. Learners are asked to identify contributing factors, and possible emotions and behaviors involved in this situation. Possible responses could include:

- Different perceptions (viewpoints)
- Disagreement over what is most important in the care activities
- Emotions of:
 - ✓ Defensiveness-responding to emotions instead of facts

- ✓ Hostility
- ✓ Judgement of Mrs. Smith as overly critical, or of staff as not caring about her husband's preferences.
- Behaviors including:
 - ✓ Lack of knowledge on the part of staff knowing the resident/family preferences
 - ✓ Lack of follow-through on the agreed plan if preferences have been discussed

Please facilitate the discussion as needed.

Handouts: None for this module.

MODULE 7:

FAMILY-STAFF PARTNERSHIPS: FORMING A PARTNERSHIP AGREEMENT

Purpose: The staff-family meeting that leads to forming a Partnership Agreement between family and staff is guided by a series of steps that guide the “negotiation session” (aka Partnership Planning Meeting). These action steps include setting a non-threatening tone for discussion, discussing family and staff views about the person’s care needs and preferences, considering both pros and cons of family and staff roles in providing care, and finalizing the Partnership Agreement. An emphasis is also placed on monitoring outcomes related to goals and RE-negotiating roles as the person’s needs change over time.

Learning Objectives:

- Discuss practices that are part of the negotiation session
- Review evaluation and renegotiation of the partnership agreement

Notes for Instructors: The content in this module is designed to supplement and expand skills to use negotiation in planning meetings. Although many organizational leaders have considerable skills in conducting care or service planning meetings that include family, the process of engaging family in discussion of how THEY would like to be involved in care (if at all), and requests they have for how STAFF provide care to their relative introduces new and different challenges.

As outlined in Module 5 instructions, much of the content in this program is directed at the skills and behaviors of organizational leaders as they conduct the negotiated partnership planning meeting. At the same time, an important part of the FIC Intervention is educating and involving daily care providers. To that end, ALL staff should understand the overall process in order to actively participate in the meeting discussion, understand and engage in roles outlined in the agreement, and be prepared to help monitor outcomes that signal the agreement is working OR that it’s time to review care needs and renegotiate goals and activities in the agreement.

Because staffing and care demands vary from setting to setting, advance planning about how these ideas apply to YOUR staff and setting is essential when applying the training ideas in practice. For example, organizational leaders will need to make additional decisions about how and when the “negotiated session” is conducted (e.g., along with a previously scheduled care or service planning meeting, or separately). Each setting will also need to decide how to monitor outcomes, and what methods are best for having staff and family each bring concerns forward about new problems or concerns (e.g., Slide 15)

Breakout Discussion/Moment: None for this module.

Handouts: None for this module.

MODULE 8: PERSON-CENTERED CARE: AN OVERVIEW

Purpose: Understanding common characteristics of person-centered care can help providers identify and use approaches, practices and routines that support being person-centered in daily care. Common values associated with person-centered care, and practices that make values visible in daily are reviewed. The importance of family involvement, and the central role of “person first” care in the Family Involvement in Care Intervention are discussed.

Learning Objectives:

- Introduce Person-Centered Care
- Link principles of being person-centered to the Family Involvement in Care Intervention

Notes for Instructors: The Family Involvement in Care (FIC) Intervention was developed BEFORE the phrase “person-centered care” was first used. However, the approaches to care that are part of the intervention are clearly designed to advance person-centered care practices. As we reviewed in the three modules about staff-family partnerships, an important focus in CARE is understanding the unique needs and characteristics of the person with dementia, including retained abilities, longstanding traits, and interests that influence preferences for daily activities and care. To best assure that person-centered care is understood and used, we have developed three inter-related modules about this topic. In this first module, we introduce the idea of what being person-centered means – both in terms of common definitions AND in practices that make “words” more meaningful.

Throughout the module there are many opportunities to use examples about individuals with dementia who are cared for in your setting. We strongly encourage leaders to think about and use personal examples, including (a) ways that staff may approach specific individuals to support the VALUES of being person centered (outlined on slide 6) and (b) specific PRACTICES that may be used in your setting to those values. The discussion of organizational culture (slide 13), in particular, is important for leaders to consider in advance of training staff. Offering some specific ideas on YOUR system level support of person-centered practices will help staff better understand what they do, as individuals, to support the process.

The last section of the module links person-centered practices back to the partnership approach. As before, there is no “one right way” to developing partnership agreements between staff and family (slide 16). However, we strongly recommend that leaders think carefully about how the Intervention Assessment, and use of Partnership Agreements can promote adoption and use of person-centered care practices in your care setting.

Breakout Discussion/Moment: None for this module.

Handouts: None for this module.

MODULE 9: STAYING PERSON-CENTERED: OPPORTUNITIES AND METHODS

Purpose: Staying “person-centered” in daily care can be helped by developing a “mind-set” about the person with dementia, his/her abilities, and how to approach and interact with the individual. Too often staff and leaders alike may mistakenly think that being “person-centered requires knowing about individual characteristics and history. Although *knowing the person well is ideal*, there are many ways to be person-centered without knowing the person well. This program reviews ways to stay “person-first” in daily interactions, and use family members as “guides” to behavior symptoms.

Learning Objectives:

- Discuss ways to be person-centered in daily interactions and cares.

Notes for Instructors: This second module on person-centered care build on content and ideas presented in Module 8. The primary aim of this module is to help both leaders and daily care providers overcome the widely held belief that person-centered care can ONLY occur AFTER staff have gotten to know the person, his/her history, habits, interests and preferences. While “knowing the person” should be the GOAL for all involved in care and treatment, there are also MANY ways that staff caregivers can communicate the VALUES of person-centered care through their approach without knowing the person well.

The main ideas related to “person first” care are highlighted on slide 5. This list can be used to discuss practices in your setting that support the main points (e.g., respect, dignity, choice). Reviewing the NDB model (slide 6) and use of the “One-Minute Assessment” (slides 7-8) are reviews that may be used to consider specific individual and care practices based on their unique needs. The remaining slides are focused on specific communication and care approaches that are associated with best care of persons with dementia. Many of these are not “new” and may be familiar to staff who have taken previous dementia training and/or learned from experience. The MAIN POINT is to counter the attitude that “I can’t be person-centered because I am new, or I don’t know this person, SO WHY TRY?” There is strong evidence that many “simple” adjustments in how staff caregivers interact with older adults with dementia can make a huge difference in outcomes, including both quality of care AND reduction of behavioral symptoms. Helping all staff adopt these practices, and at the same time work to “get to know” the person with dementia, can vastly improve quality of work life for staff, and outcomes for those with dementia. Staff leaders are encouraged to think about the “culture of care” discussed in Module 8, and how practices can be integrated into daily care as the standard of care in your setting.

Breakout Discussion/Moment: This module includes a situational breakout discussion. Learners are shown an image of an older adult who appears to be in distress and asked to use the “one-minute assessment” to determine possible reasons for her distress and supportive approaches to provide care.

Possible reasons for the person's distress could include:

- Feelings of confusion about where she is and what is going on
- Headache or other physical pain that is distressing to her
- Feeling sad or upset about something that has just happened, such as a phone call or hearing something on the morning news

There are no right or wrong answers and many possibilities. Answers might also be guided by whether or not staff KNOW Mrs. Jones, and so may have some clues about what her behavior may mean.

Please facilitate the conversation as needed and continue the presentation when the learners are ready.

Handouts: None for this module.

MODULE 10:
KNOWING THE PERSON WITH DEMENTIA: *LET ME INTRODUCE YOU TO...*

Purpose: High quality care is promoted by knowing the person with dementia. However, learning about both current and longstanding characteristics, interests, and preferences can be challenging when memory and language problems interfere with the person “telling their story” to staff. This program reviews both traditional and novel ways that staff and family may collaborate to develop “life stories” -- important characteristics, values, or experiences of the person with dementia – that may help guide daily care and activities.

Learning Objectives:

- Discuss traditional and novel methods for developing “life stories” to guide daily care

Notes for Instructors: In this third module about person-centered dementia care we re-focus on both the importance of knowing the person, and approaches to do that AND then share information with other caregivers. As outlined below, we start by asking learners to think about what THEY would want caregivers to know about their personal interests and needs if they were unable to communicate those things. You may wish to expand that discussion to personal experiences they have already had with being a family member of a person with dementia (e.g., daughter/son; granddaughter/son; spouse for some older team members). From there we expand to review a variety of approaches that may be used to gather information about the person with dementia AND share it with other team members.

Please note that a variety of handouts accompany this module and are referenced in the presentation. We strongly encourage leaders to compare these approaches to ones that may already be in use in your care setting. The point is not to replace approaches that are working well, but rather to introduce ideas that compliment or expand what is already in place. And because the person with dementia is often not able to recall information, there are many opportunities to involve family in gathering information AND expanding on or clarifying information the person with dementia provided. We strongly encourage staff to talk directly with the person who has dementia – asking him/her questions about personal interests, habits, work and leisure history, and daily routines. At the same time, asking questions can feel a little like “being tested” and become uncomfortable if the person cannot recall answers or information about the past. In turn, family become a very important source of information.

At the conclusion of this module we return to the idea of behavioral symptoms, and how the NDB model can help both staff and family caregivers better understand the meaning of behaviors. In this module the greater emphasis is Individual Factors that tend to be stable and longstanding. The point is to emphasize that knowing “individual” information can help staff be person-centered AND, at the same time, can help them understand how those factors may influences the occurrence of behavioral and psychological symptoms (aka problem behaviors).

Breakout Discussion/Moment 1 (slide 4): Ask learners to imagine that they have dementia and had someone providing care for them. What types of special preferences or routines would they want their care provider to know about them? Many examples are possible:

- How they take their coffee
- How they like to have their hair styled
- What time they like to rise/go to bed
- Favorite foods OR foods to never serve them
- Favorite activities or pastimes
- Lot of options

Please facilitate the discussion as needed, remembering there are no right or wrong answers. Consider asking HOW their caregivers might learn these things, and what that means in their care of older people with dementia. The goal is to help staff caregivers better understand how seemingly “small things” can make all the difference in quality of living. By “reversing roles” with the person with dementia we hope they can look at caregiving from a different viewpoint.

Handouts:

- Know My Preferences form
- My Life Story form
- My Top 5 form

MODULE 11: GOAL-DIRECTED CARE: IDENTIFYING AND USING VALUES TO DIRECT DECISIONS

Purpose: The goals of dementia care often change as the disease progresses. Identifying personal and family values may help guide care decisions, including those that involve “risks”. Early discussions and information-sharing with family related to their values and goals may reduce both stress and crisis-based decisions, and advance “person-centered” (individualized) care and treatment decisions.

Learning Objectives: Define goals of health care and treatment

- Consider individual and family values in relation to goals
- Establish practices to guide family discussions

Notes for Instructors: In this module we return to basic ideas about the progression of dementia and how care needs and preference often change at the person becomes more disabled. Because the loss of abilities in dementia is slow but progressive, it’s important for both staff and family caregivers to ANTICIPATE what may occur so they are not “caught off guard” by behaviors, OR continue to expect the person to perform in ways that are no longer reasonable. Unrealistic expectations are a common cause of both behavioral symptoms for persons with dementia, AND conflict between staff and family caregivers. Having a shared understanding of how dementia will change the person and his/her abilities over time, and also what that means in terms of setting reasonable goals for daily life, is essential to high quality care. To that end, we review the stages of dementia and how goals shift from the early to middle and later stages of dementia.

We then introduce the idea of “collaborative goal setting.” This is really just an extension of the planning and discussion that occurs in family-staff care planning meetings and “negotiated sessions” that aim to find mutually satisfying goals and activities. The main difference is that a greater focus is place on the person’s and family’s VALUES, the beliefs that guide their decisions. As you talk about values and beliefs, work to repeat the “motto” on slide 8: “It’s not hard to make decisions once you know what your values are.” This points to the fact that too many times we all are on “automatic pilot” – making decisions without thinking carefully about how they fit with our values and beliefs. Another important issues is that family members may have deep conflicts between what they “know” intellectually about what their loved one would want for themselves, and how they “feel”, themselves. For example, family may “know” that mom does not want to linger or suffer and has said that repeatedly. In turn, sending mom to the hospital to treat acute illness like pneumonia does not “fit” with mom’s request. However, family feel “guilty” and worry mom will suffer, OR that others may think they are uncaring and trying to end mom’s life. Those thought and feelings may not be “conscious” and will only come out through discussion. In short, identifying values, and then moving values to goals of care can help

reduce making decisions in the moment of “crisis” AND help assure that the person’s and family’s real wishes and goals are respected.

We review three broad goals of care, and then talk about dementia-related goals of care that are often the focus in collaborative goal-setting discussions. We strongly urge leaders to use the same principles of staff-family partnerships as you think about goal-setting discussions. The true “bottom line” is that families and staff must both be EDUCATED about changed abilities and goals of care, and help to understand that interventions like hospitalization, preventive health activities, and medication use are all targets of discussion. This discussion is foundational to the next program, Comfort Care in Dementia Care that addresses use of palliative care approaches to advance wellbeing in the advanced stages of dementia.

Breakout Discussion/Moment: None for this module.

Handouts:

- Stages of Dementia
- SMART+

MODULE 12: COMFORT CARE IN DEMENTIA CARE: FAMILY INVOLVEMENT IN ADVANCED PLANNING

Purpose: This program expands the ideas of goal-directed care by reviewing often predictable end-of-life changes and issues in dementia. The “hospice approach” to dementia care offers a step-wise palliative care approach to collaborative goal setting between staff and family caregivers. The goal is to help families plan ahead by discussing issues that are common in later-stage dementia and supporting the person’s wishes.

Learning Objectives:

- Describe the importance of palliative care in dementia care
- Promote advanced planning to reduce stress and crisis-based decisions

Notes for Instructors: The content in this module is based on longstanding, evidence-based practices that were developed in a Veteran’s Administration (VA) geriatric research and education center in the 1980s before palliative care became common. Leaders at the VA center observed a need for family to better understand changing needs as dementia progressed into the late stage and became “terminal.” In this module, we review the progressive loss of abilities in dementia and introduce the idea of “palliative care.” Palliative care now extends “comfort care” beyond hospice – which is more widely understood, but is often more restrictive by being time-limited, and is under used in dementia care.

The content extends and builds on the nationwide movement toward advance care planning and documentation to support “honoring wishes” of all people, not just those with dementia. We introduce palliative care as a means to address comfort in advanced dementia, with a goal of helping staff (and in turn, family) understand the various ways that pain is experienced in dementia – including both physical pain and psychological pain (slide 6). Advanced care planning is BEST conducted when the person with dementia is still able to be part of the discussion. And even if that time has passed, it continues to be important to start conversations with family members before they are faced with common decision in the end stage of dementia. It often takes time for family members to truly understand and use information that may seem contrary to their usual beliefs. For example, the decision to NOT send a loved one to the hospital will likely take several conversations that emphasize how confusing and distressing the experience is to persons with dementia, and that similar care can often be provided without the “transfer trauma” of hospitalization.

Many settings have already adopted the nationally known Physician Order of Life-Sustaining Treatment (POLST) (slide 7). Our goal is to build on those ideas by reviewing specific care questions (aka, burdensome care) that often arise in the course of dementia. We also introduce the step-wise “Hospice Approach” that encourages recurring discussions and decision-making with families as the dementia progresses. Like most things, there is “no one right way” to

approaching decisions related to burdensome care. The main goal is to introduce the idea that treatments in late stage dementia can cause both distress and discomfort to the person with dementia. It's not as "clear cut" as many people – staff and family alike – may think. Starting the conversation early in the relationship with the family and person with dementia increase the likelihood that "crisis care" decisions may be avoided, AND the person with dementia is provided high quality COMFORT care.

POLST VS. IPOST

POLST stands for Physician Order for Life-Sustaining Treatment and is a medical order for the specific medical treatments desired during a medical emergency. POLST forms do not replace advance directives, but rather, they work together. POLST may be called different things in different states. The link provided here outlines the National POLST Programs along with state initiatives. <http://polst.org/programs-in-your-state/>

The state of Iowa, for example, utilizes a program called IPOST-Iowa Physician Orders for Scope of Treatment. The IPOST form is a double-sided, one-page, salmon-colored form that indicates the individual's preferences for life-sustaining treatments to provide clear direction during medical emergencies. For more information on the IPOST program follow this link: <https://www.ihconline.org/additional-tools/initiatives/ipost/>

Breakout Discussion/Moment: None for this module.

Handouts:

- Common Sources of Burdensome Care
- Hospice Care Overview
- IPOST

V. SIGNING INTO THE IOWA GERIATRIC EDUCATION CENTER

The Iowa Geriatric Education Center website offers a wide variety of free education, including the family-focused training series called *Family Involvement in Care: Advancing Care Partnerships* (abbreviated as FIC on the website). We provide instructions about logging on to the site to best assure that the requirements are not a deterrent to using the FIC training series.

The information that you provide when registering will be used for aggregate reporting purposes only, so that the Iowa Geriatric Education Center (IGEC) may continue to offer geriatric education at no cost. Please contact the IGEC at geriatric-education@uiowa.edu with any questions or for more information.

The Iowa Geriatric Education Center is located at <https://igec.uiowa.edu/> and will look like this. The main pictures rotate so you may not see the one of the Topeka Palliative Care Fair pictured here, but other features will be the same. Note that **the link to FIC** training is located in the top blue bar, **User Registration** is in the center, and the **Login** link is at the top right. All are circled in **red** here.

The screenshot displays the Iowa Geriatric Education Center website. The top navigation bar is dark blue with the site name in white. The 'FIC' link is circled in red. The 'Login' link in the top right is also circled in red. The main content area features a large image of a fair with the caption 'Topeka VA Palliative Care Fair'. Below this, the 'User Registration' link is highlighted with a red border, indicating it is the focus of the instructions.

Click on User Registration the first time you visit the site.

The next screen will look like this. Select the type of account that best fits you. The answer does not affect your access to training materials, but does guide the type of questions you are asked in the next screen. Family member should select “Family Caregiver or Patient.” Click on Submit.

Iowa Geriatric Education Center

HOME GERIALEARNING GLS SBIRT+ IA-ADAPT DELIRIUM FRAILTY FIC

User Account Registration

Home > User Account Registration

If you already have a user account, login at the [user page](#).

If you would like to create a user account, please select an option below to register.

Which type of account would you like to create? *

- Direct Care Worker (Certified Nursing Assistant, Home Health Aide, Personal Care Assistant, or similar occupations)
- Faculty (person designated to provide instruction in an organization)
- Family Caregiver or Patient
- Health Care Professional (Allied Health, Behavioral Health, Dentistry, Medicine, Nursing, Physician Assistant, Public Health, Other)
- Student

Submit

The next screen will look like this. Notice that you will need to create a “Username” – which allow spaces but not punctuation other than periods, hyphens, apostrophes and underscores. The **red asterisks *** mean the answer is required.

IOWA GERIATRIC EDUCATION CENTER

HOME
GERIALEARNING
GLS
SBIRT+
IA-ADAPT
DELIRIUM
FRAILITY
FIC

Home > Log in > Create new account

Create new account
Log in
Request new password

Username *

Spaces are allowed; punctuation is not allowed except for periods, hyphens, apostrophes, and underscores.

E-mail address *

A valid e-mail address. All e-mails from the system will be sent to this address. The e-mail address is not made public and will only be used if you wish to receive a new password or wish to receive certain news or notifications by e-mail.

Family/Lay Caregiver or Patient Profile Information

I am a *

Family Caregiver
 Lay Caregiver
 Patient

Age Group *

Gender *

The information continues on the next page.

Gender *

Race *

Are you Hispanic/Latino? *

Yes
 No

What is the Zip Code of your residence? *

Enter your 5-digit Zip Code. If you are located outside of the US, enter 99999 for the Zip.

How long have you been a caregiver for this person? *

After you click on “Create new account” you are directed to the page “About Us.” At the same time, you are sent an EMAIL that offers the following information. Note that the link is personalized to YOU. (E.g., do not try to use the one provided in the example below).

Thank you for registering at Iowa Geriatric Education Center. You may now log in by clicking this link or copying and pasting it to your browser:

<https://igec.uiowa.edu/user/reset/21431/1534082919/9x5lmnTQPsp3Gs4iG2Y6epiO9GpJWc-TLy9e9AhLAEc>

This link can only be used once to log in and will lead you to a page where you can set your password.

After setting your password, you will be able to log in at <https://igec.uiowa.edu/user> in the future using:

username: [Your username is here]

password: Your password

-- Iowa Geriatric Education Center team

When you click on the link provided in the email, you are directed to a page that looks like the screen at the top of the following page.

The screenshot shows the top portion of the Iowa Geriatric Education Center website. At the top right, there are links for "About Us", "Quick Links", and "Login". The main header reads "IOWA GERIATRIC EDUCATION CENTER". Below this is a dark blue navigation bar with the following menu items: HOME, GERIALEARNING, GLS, SBIRT+, IA-ADAPT, DELIRIUM, FRAILTY, and FIC. The main content area shows a breadcrumb trail: Home » User account » Reset password. Below the breadcrumb, it states: "This is a one-time login for *Smith-M* and will expire on *Mon, 08/13/2018 - 09:08*". It then says: "Click on this button to log in to the site and change your password." and "This login can be used only once." At the bottom of this section is a blue "Log in" button.

When you click on “Log in” and you are sent to the page where you can set your password.

IOWA GERIATRIC EDUCATION CENTER

HOME GERIALEARNING GLS SBIRT+ IA-ADAPT DELIRIUM FRAILTY FIC

Home » My account » Smith-M » Edit

You have just used your one-time login link. It is no longer necessary to use this link to log in. Please change your password. ✕

View Edit

E-mail address *

Marianne-smith@uiowa.edu

A valid e-mail address. All e-mails from the system will be sent to this address. The e-mail address is not made public and will only be used if you wish to receive a new password or wish to receive certain news or notifications by e-mail.

Password

..... Password strength: Strong

Confirm password

..... Passwords match: yes

To change the current user password, enter the new password in both fields.

Picture

Upload picture

No file selected.

Your virtual face or picture. Pictures larger than 1024x1024 pixels will be scaled down.

When you click on Save, you are again sent to the “About us” page. At the top in the right hand corner is the link to Log in.

The image on the following page will appear.

From now on, all you need to do is click on “Login” at the top of the webpage and enter your unique Username and Password.

Iowa Geriatric Education Center

HOME GERIALEARNING GLS SBIRT+ IA-ADAPT DELIRIUM FRAILTY FIC

Home > User account

Log in Request new password

Username *

Enter your Iowa Geriatric Education Center username.

Password *

Enter the password that accompanies your username.

Log in

We highly recommend writing down both your Username and Password in an easy-to-find location.

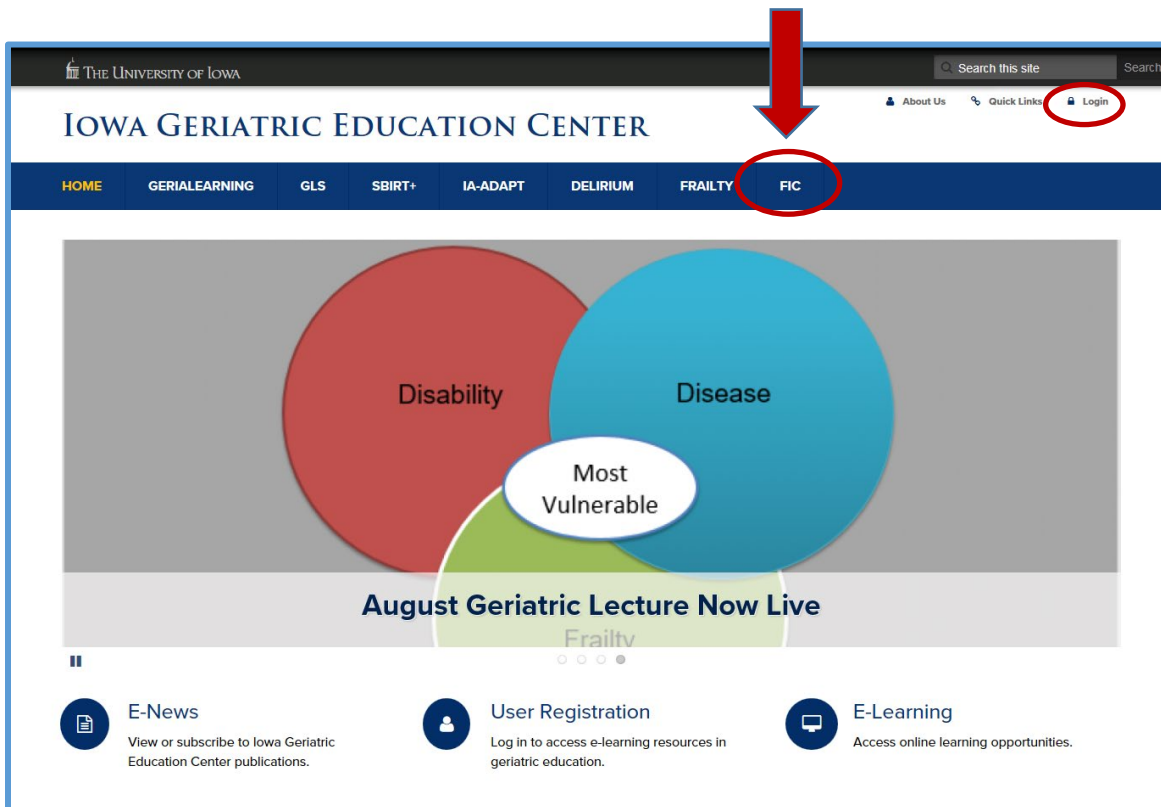
USERNAME: _____

PASSWORD: _____

VI. ACCESSING THE FAMILY INVOLVEMENT IN CARE TRAINING SERIES

The Iowa Geriatric Education Center website offers a wide variety of free education, including the family-focused training series called *Family Involvement in Care: Advancing Care Partnerships* (abbreviated as FIC on the website). We provide instructions about logging on to the site to best assure that the requirements are not a deterrent to using the FIC training series.

The Iowa Geriatric Education Center is located at <https://igec.uiowa.edu/> and will look like this.



Once you are registered and logged onto the Iowa Geriatric Education Center click on “FIC” on the far right of the upper banner.

IOWA GERIATRIC EDUCATION CENTER

HOME GERIABLEARNING GLS SBIRT+ IA-ADAPT DELIRIUM FRAILTY **FIC**

Family Involvement in Care (FIC)

Home > Family Involvement in Care (FIC)

The progressive loss of abilities in dementia often results in family members caring for their loved ones as the disease advances. Studies show that when family and health care providers approach care as a partnership, better outcomes occur. The overarching goal of the Family Involvement in Care (FIC) program is to help families and providers work together to provide the highest quality of person-centered care possible.

Background

Why is family involvement in care so important?

Training

This content series covers topics such as communicating with caregivers, negotiating on behalf of your loved one, how to ask difficult questions, managing medications, and more.

Resources

View the resources we have available to help family members act as partners in care.

On the next page select “Training”.

IOWA GERIATRIC EDUCATION CENTER

HOME GERIABLEARNING GLS SBIRT+ IA-ADAPT DELIRIUM FRAILTY **FIC**

Training

Home > Family Involvement in Care (FIC) > Training

Welcome to the Family Involvement in Care Series. Because it is designed using the University of Iowa Virtual Classroom, this curriculum may look slightly different than our other courses that you have used.

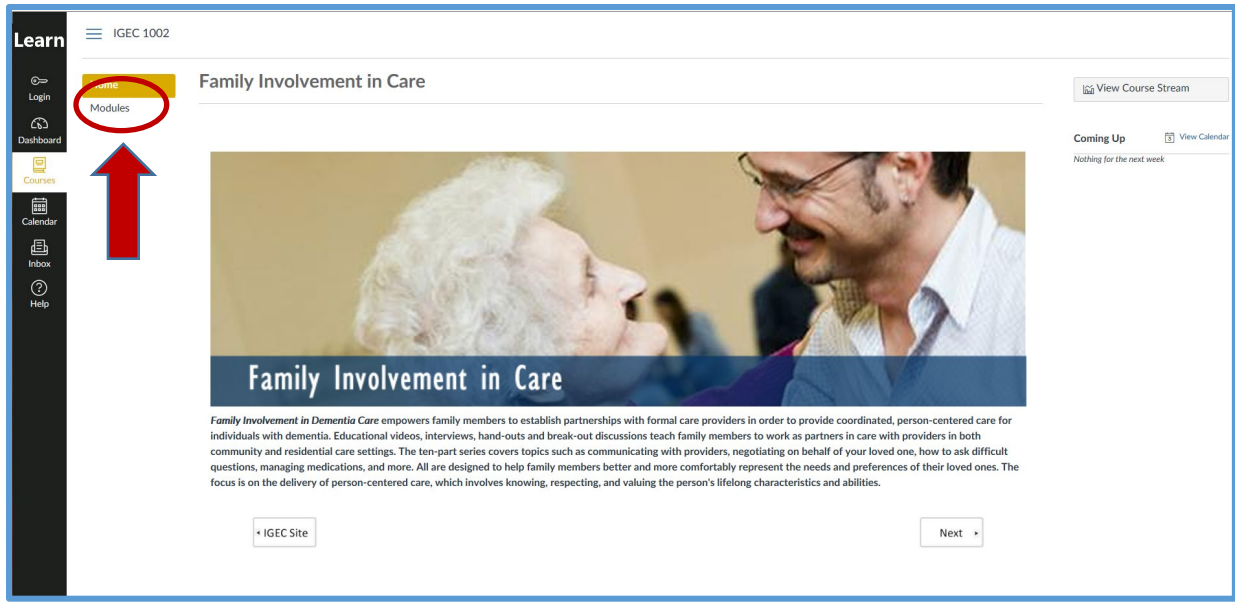
Click the blue button below to begin. After you enter the training, you will see a black toolbar in the left margin, which is for University of Iowa student access. You will navigate this training by clicking on “Next” at the bottom right of the screen. You may return to our home page at any time by clicking the button that reads, “IGEC Site.”

[Go to the Family Involvement in Care Series](#)

Family Involvement in Care (FIC)

- > Family Involvement in Care (FIC)
- > Background
- > Training
- > Resources

Next click “Go to the Family Involvement in Care Series”.



Learn IGEC 1002

Home
Modules

Family Involvement in Care

View Course Stream

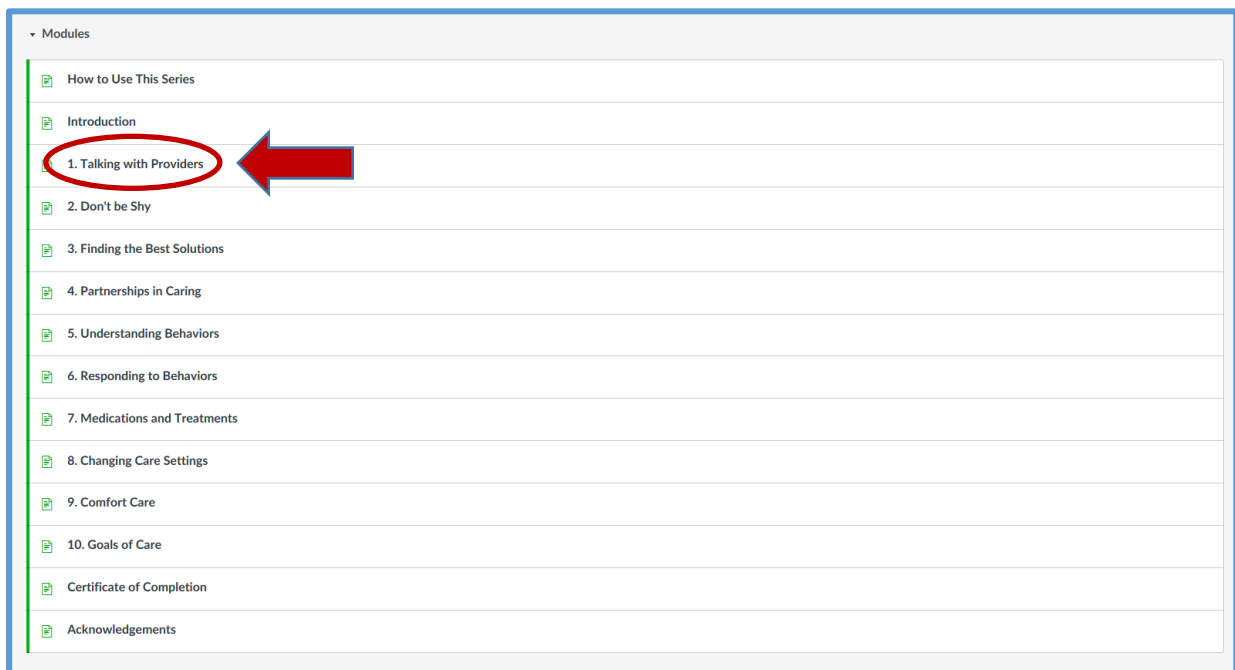
Coming Up
View Calendar
Nothing for the next week

Family Involvement in Care

Family Involvement in Dementia Care empowers family members to establish partnerships with formal care providers in order to provide coordinated, person-centered care for individuals with dementia. Educational videos, interviews, hand-outs and break-out discussions teach family members to work as partners in care with providers in both community and residential care settings. The ten-part series covers topics such as communicating with providers, negotiating on behalf of your loved one, how to ask difficult questions, managing medications, and more. All are designed to help family members better and more comfortably represent the needs and preferences of their loved ones. The focus is on the delivery of person-centered care, which involves knowing, respecting, and valuing the person's lifelong characteristics and abilities.

IGEC Site Next

Once you are to this page you can navigate and select the modules you wish to view by clicking “Modules”



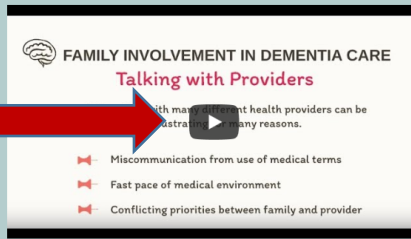
Modules

- How to Use This Series
- Introduction
- 1. Talking with Providers
- 2. Don't be Shy
- 3. Finding the Best Solutions
- 4. Partnerships in Caring
- 5. Understanding Behaviors
- 6. Responding to Behaviors
- 7. Medications and Treatments
- 8. Changing Care Settings
- 9. Comfort Care
- 10. Goals of Care
- Certificate of Completion
- Acknowledgements

The information builds throughout the series so we suggest starting with Module 1.

1. Talking with Providers

[Presentation \(14:27\)](#) [Pearls of Wisdom \(4:07\)](#) [Related Resources](#) [Satisfaction Survey](#)



The thumbnail features a brain icon in the top left corner. The main title is "FAMILY INVOLVEMENT IN DEMENTIA CARE" in a bold, black font. Below this, the subtitle "Talking with Providers" is written in a pink font. A red arrow points from the left towards a play button icon in the center. To the right of the play button, there is a short paragraph of text: "With management health providers can be frustrated for many reasons." Below this text is a bulleted list with three items, each preceded by a red double-headed arrow icon: "Miscommunication from use of medical terms", "Fast pace of medical environment", and "Conflicting priorities between family and provider".

[Take-Away Messages](#)

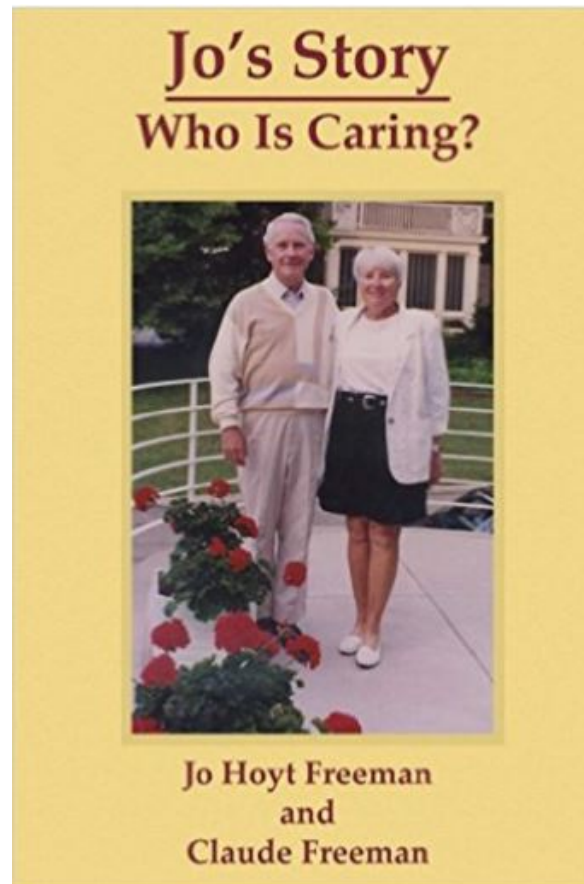
◀ Previous

Next ▶

APPENDIX 1: SPECIAL THANKS TO OUR FUNDING SOURCE

As we noted on the last slide of Module 1, Introduction and Overview, we would like to thank our funding source, the **Jo Hoyt Freeman Dementia Education and Outreach Fund Person-Centered Care Initiative** that is hosted by the Barbara and Richard Csomay Center for Gerontological Excellence at the University of Iowa, College of Nursing.

We also wish to acknowledge the book that has been distributed as part of this project, and is available at no cost through the Csomay Center.



To receive a copy or copies of this book, please email your name, mailing address, and number of copies requested to the Csomay Center: Csomay-Center@uiowa.edu

We would also like to thank Mr. Freeman for his thoughtful review of progress and materials throughout the development of this training series.

APPENDIX 2: SPECIAL THANKS TO LEADERS AND CONTRIBUTORS

Many individuals were essential to the development of our 12-part training series.

All aspects of the *Partnership to Improve Care and Quality of Life for Persons with Dementia* training project were conducted under the leadership of Jill Colbert, Study Coordinator.

Dianne Spring-Brenneman and Kathleen C. Buckwalter who conducted the original FIC Intervention study on which materials are based served as consultants related to the training content.

Technical support and assistance was provided by Csomay Center team members Megan Dotson, Ryleigh Maas, and Eiko Oka.

We wish to acknowledge the many staff members and their senior living communities who served as our partners in the development, review, and critique of the training materials. Many providers provided their volunteer assistance multiple times during the two year development process, and we are very grateful for their time, insights, and suggestions!

- Bickford Senior Living, Iowa City, IA
- Amana Retirement Community, Amana, IA
- Crestview Specialty Care, West Branch, IA
- Friendship Village Community, Waterloo, IA
- Halcyon House, A Wesley Life Community, Washington, IA
- Keystone Cedars Assisted Living, Cedar Rapids, IA
- Legacy Retirement Community, Iowa City, IA
- Oaknoll Retirement Community, Iowa City, IA
- Meth-Wick Community, Cedar Rapids, IA
- Pioneer Park, Lone Tree, IA
- Simpson Memorial Home Inc., West Liberty, IA
- Solon Retirement Village, Solon, IA
- Stonehill Health Center, Dubuque, IA
- Sunrise Terrace Care Center, Winfield, IA
- Western Home Communities, Cedar Falls, IA
- Wilton Retirement, Wilton, IA