

# OASIS 1.3

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## TRAINING MANUAL for TRAINERS 2012

Originally developed with support from the Massachusetts Extended Care Career Ladder Initiative (ECCLI). Revised, 2011 with support from Commonwealth Corporation and Massachusetts Senior Care. Revised, 2012 for Massachusetts Senior Care in conjunction with CMS Partnership Initiative to Improve Dementia Care. ©Susan Wehry, M.D. 2010, 2012

## Introduction

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### Welcome to OASIS 1.3

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What is OASIS? Literally, an oasis is a fertile spot in a desert where water is found. Figuratively, it is a pleasant or peaceful area or period in the midst of a difficult, troubled, or hectic place or situation. This OASIS is an interdisciplinary approach to care based on the author's 25 years of clinical experience and validated by the research of Thomas Kitwood and Jiska Cohen-Mansfield. It is an approach that emphasizes personhood over patienthood.

The unique OASIS curriculum is designed to assist staff in dealing with the everyday needs and challenges of today's long-term care population. We believe it will provide staff with the knowledge, skills and attitudes needed to feel confident, competent and calm no matter how hectic or difficult the situation.

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### Why do we need OASIS?

The nursing home business is changing. Individualized, person-centered care is replacing institutionalized care, a greater emphasis on home-like environments is replacing a purely medical model, and quality of life concerns are becoming equal in importance to quality of care issues.

Long-term care facilities are now home to many different people. Young adults with complex medical and neuropsychiatric needs due to brain injuries or serious and persistent mental illness live alongside older adults with challenging behavioral syndromes associated with dementia. Persons of all ages with mixed disabilities may stay for a short time or a lifetime.

To date, staff training has not kept pace with these changes. As a result, staffs are facing more incidents of resident - to - resident and resident-to- staff aggression. Staff burnout from working with this changing population has increased. Burnout can lead to high turnover.

The OASIS curriculum was developed to be specific for the needs and strengths of the current population in long-term care.

**This curriculum applies to all employees.**

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## How is OASIS different?

**The OASIS curriculum focuses on who the person is, not just what he or she has.** It focuses on strengths, wants, needs and personal goals in addition to the disability or health care need. The goal of the curriculum is to help create a safe, secure environment geared toward successful outcomes. This includes improved functional status. OASIS addresses challenging behaviors by focusing on understanding and addressing residents' unmet needs. This goes a long way towards improving quality of life, reducing overreliance on unnecessary medications and preventing excess disability.

What is excess disability? Excess disability refers to the loss of ability to function due to factors other than those due to the disorder itself (dementia, schizophrenia or traumatic brain injury). Why focus on excess disability?

**Excess disability both increases the amount of care required and diminishes the quality of life for the resident.**

Excess disability is common in facilities with many younger people with psychiatric disabilities. Excess disability results in poorer quality of life. Excess disability increases demands on staff. Concentrating on what a person can do, rather than on what they can't do, can prevent excess disability. Building on what a person can still do results in better adjustment to the environment. Building on what a person can still do improves life satisfaction for residents and staff. Building on what a person can still do reduces burden for already busy caregivers.

Unlike the traditional, diagnosis-centered maintenance approaches to long-term care, building on what a person can still do is preferable because it:

- creates an atmosphere geared toward successful outcomes
- improves function
- supports recovery
- is consistent with the Centers for Medicare and Medicaid Services (CMS) quality of life guidelines

**OASIS is also different in that it recognizes the unique learning style of adults.** OASIS facilitators know that staff brings valuable knowledge, skills and life experiences to the classroom. Active participation is critical if learning is to be of any lasting value.

Staffs learn best if OASIS helps do the job. With this in mind, we **ask participants to name one learning goal at the start of each learning encounter.**

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## Why OASIS 1.3?

The OASIS curriculum evolves in response to new evidence about what works. OASIS 1.3 incorporates the recommendations derived from the 2011 Massachusetts demonstration project led by Massachusetts Senior Care.

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## OASIS design

**OASIS works best** when the designated OASIS coordinator and OASIS trainer assume the role of champions for this model. Champions are visible on the units and actively seek out “just in time” learning opportunities grounded in day-to-day experience. Champions build “buzz” for OASIS by engaging staff, family and residents prior to the roll-out of the curriculum and help maintain momentum by incorporating OASIS moments into everyday care practices and in every in-service.

The OASIS curriculum has 4 modules and provides 8-10 hours of learning activities. It is laid out much like a syllabus that can be used to create your own learning plans. The curriculum is designed to be presented sequentially; each successive module builds on learning from the previous models. The modules are:

### Module I: (75-90 minutes) Kick-off session: Welcome to OASIS The Changing Face of Long-Term Care

What is OASIS? Why do we need a new curriculum? How will it help me? How will it help our residents? Who are the individuals residing in our homes? What needs and strengths might they hold in common? How can we create the kind of neighborhoods residents want to live in and we want to work in? This module begins the shift from Patienthood to Personhood. Another way to say this is that it sets the stage for furthering the use of Person-Centered Care and Support Plans and away from exclusively Disease-Centered Care. This theme runs throughout OASIS. **Intended for use with all Staff, Managers and Administrators.** May also be adapted for use with families and resident councils.

### Module II: (1 hour) Person Centered Care and the Recovery Model

What is recovery? What do we mean by person-centered and resident-directed care? How does it impact care planning? How do you make strength-based care plans with individuals who have dementia? This module demonstrates how individuals can live with hope, meaning and high quality of life in the long term care setting. **Intended for use with all Staff and Managers.** May also be adapted for use with families and resident councils.

### Module III: All About Behavior (4 hours)

What do we mean by the statement all behavior is communication? How can we best understand and address common challenging encounters? This module teaches staff how unmet needs drive most disruptive behaviors and provides tools for asking: what is this resident trying to tell us and how should we respond? How can we best keep residents and ourselves safe? What are the best techniques for providing care to a resident with a history of aggressive behaviors? **Intended for use with all Staff and Managers.**

### Module IV: Institutional practices (75-90 minutes)

This module emphasizes institutional practices that support personhood and deal with crises and challenging behaviors by preventing them from occurring in the first place. **Intended for use with all Staff, Managers and Administrators.**

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## Expected Outcomes

### Goals

We expect staff to acquire the knowledge, skills and attitude to:

- Provide person-centered support and care to a broad range of residents;
- Maintain safety and security for all residents as well as themselves;
- Help all residents obtain the highest practicable quality of life

### Objectives

After completing the OASIS curriculum staff will be able to:

- Report more confidence in working with a variety of people
- Demonstrate more skill in addressing needs
- Engage in active learning that extends beyond the classroom
- Adopt a strength-based approach to individualized care plans
- Support all residents' efforts towards recovery

### Indicators

If OASIS succeeds, staff and residents will have a greater sense of safety, security and quality of life as evidenced by:

- Reduction in inappropriate use of antipsychotics
- Higher rates of consumer satisfaction when surveyed
- Higher rates of staff satisfaction when surveyed
- Fewer resident incidents
- Reduced staff turnover
- Institutional practices reflective of culture change in care, workplace and environment

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## Guide for Facilitators and Champions

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### Overview of Adult Learning

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Respect for the adult learner's unique learning style forms the foundation of this curriculum and this companion guide. **Adult learners bring valuable knowledge, skills and life experiences to the learning encounter.** Much can be learned by reflection and discussion of one's life and work experience. **Active participation is critical if learning is to be of any lasting value.**

Adults learn best when they feel the content is going to be useful. With this in mind, each module has been created with an eye to what staff might find "fun to know" and "good to know" but emphasizes what staff "need to know" to translate classroom learning to their jobs.

Facilities (owners, administrators, supervisors) are more willing to adopt new practices when they feel the practices are based in something more than the personal preferences, beliefs and style of the curriculum designer. With this in mind, the content and strategies for delivery are grounded in known, evidence-based training practices where possible and with attention to the regulatory and quality improvement dictates in the long term care world.

*Not all learning takes place in the classroom; in fact, for adults, most of it doesn't.*

The adult learner is a person with a sense of self, bringing all previous life experiences, both personal and professional, to bear on new learning. Adults learn best when new learning is demonstrably tied to or built upon past experiences. Adults can learn well -and much - from dialogue with respected peers. OASIS trainers are referred to as facilitators to underscore this fact.

Unlike children and teenagers, adults have many responsibilities they must balance against the demands of learning. Because of these responsibilities, adults have barriers against participating in learning. Some of these barriers include lack of time, money, confidence, interest, scheduling problems, "red tape," and problems with childcare and transportation.

Programs need to be designed to accept viewpoints from people in different life stages and with different value "sets." A concept needs to be "anchored" or explained from more than one value set and appeal to more than one developmental life stage. **Recommendation: Discuss with a colleague what the practical implications of this might be.**

The adult learner controls what is learned, selecting new information and/or deciding how to use it, and this takes place at both the conscious and unconscious levels.

Adults exhibit a variety of learning styles. They learn in different ways at different times and for varying reasons.

**Adults tend to be problem-centered rather than subject-centered learners and learn best through practical applications of what they have learned.**

New learning is followed by a period of reflection to facilitate integration and application of new knowledge and skills. Adults need to be able to integrate new ideas with what they already know if they are going to keep - and use - the new information.

Information that conflicts sharply with what is already held to be true, and thus forces a re-evaluation of the old material, is integrated more slowly.

Adults tend to take errors personally and are more likely to let them affect self-esteem. Therefore, they tend to apply tried-and-true solutions and take fewer risks.

Adults have something real to lose in a classroom situation. Self-esteem and ego are on the line when they are asked to risk trying a new behavior in front of peers and cohorts. Bad experiences in traditional education, feelings about authority and the preoccupation with events outside the classroom affect in-class experience.

Adult learners must be treated as adults and respected as self-directed persons. They **learn best in non-threatening environments** of trust and mutual respect.

Adults prefer self-directed and self-designed learning projects to group-learning experiences led by a professional. They select more than one medium for learning, and they desire to control pace and start/stop time.

Regardless of media, straightforward how-to is the preferred content orientation. Adults cite a need for application and how-to information as the primary motivation for beginning a learning project.

Adults have expectations, and it is critical to take time early on to **clarify and articulate all expectations before getting into content**. The facilitator can assume responsibility only for his or her own expectations, not for those of students.

**New knowledge has to be integrated with previous knowledge;** students must actively participate in the learning experience. The learner is dependent on the facilitator for confirming feedback on skill practice; the facilitator is dependent on the learner for feedback about curriculum and in-class performance.

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## Objectives and Strategies

Learning objectives may be directed toward the acquisition of knowledge, skills or attitude. Different learning strategies have been suggested for each module to support the kind of learning objective that is sought. The facilitator should feel free to develop his or her own strategies as well.

For example:

*You would like participants to gain new facts and information.* Strategies: Discussion, mini-lectures, audiovisual materials, recordings, readings, handouts

*You would like participants to apply the newly learned concepts or knowledge.* Strategies: Group discussion, demonstrations, case studies, participatory exercises, role-playing, simulations

*You would like participants to examine and/or acquire helping attitudes, opinions, and values.* Strategies: Experience sharing, case study, role-play, films, guided discussions

Examples:

- **Audio-visual** - Recordings, slides, films, DVDs, podcasts
- **Case study** - Group discussion and problem solving based on an actual situation
- **Experiential learning** - On the job training followed by reflection on the activity
- **Handout** - Easily referenced written materials prepared to carry away from the training, place in resource book
- **Lecture** - A short lecture to convey specific information or theoretical background
- **Role-play** - Design for learning in which participants act out a situation through assigned parts that they play spontaneously.
- **Self-assessment tools**- Anonymous questionnaires and check list requesting participants to examine and/or evaluate their own situations, needs, values, attitudes, or beliefs.
- **OASIS moments** - Incorporate a single “personhood” success story that occurred during the preceding 24 hour period into the daily huddle

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## Design

The OASIS curriculum consists of four key modules designed for the adult learner; **lecture time should be kept to a minimum** and materials for practice or further learning in-between sessions are provided. Module III will require several sessions for completion.

Each module includes a well-defined set of learning objectives and suggested strategies for presenting the material; a pre and post test; a PowerPoint presentation which can be used as a slide show, to create overheads, notes or handouts; exercises; and suggestions for supplemental reading and between session learning activities.

The manual contains a glossary and a list of additional resources and recommended reading for the motivated staff member. As not all learning takes place in the classroom, facilitators are advised to encourage staff to explore these additional resources.

Modules build on one another sequentially and should be given in order.

**Each facilitator should familiarize him/herself with the entire contents of the training manual before rolling out OASIS.**

**At each session, you should:**

- Set up the classroom prior to the training so you can greet your participants as they enter the room.
- Introduce yourself and pass out tent cards and ask each person to write the name by which they like to be addressed
- Begin each session with a brief overview of the purpose of OASIS and define the goals and objectives of the module under study;
- Ask each participant to define one personal learning goal for the session;
- Set out the plan for achieving them;
- Use the pre- (and post)-tests to launch a discussion OR as a written test; most facilities found that the written tests were a barrier to full participation but this was not universally true; and,
- If using the written pre/post tests, hand out or read the pre-test and explain that unlike many tests, this one is designed to show how much participants know, as well as how much they do not. In this way they can see how much they have learned. To help ease participants anxiety you might explain these exercises are not graded and that no one sees them except the facilitator. You may also explain that the pre and post exer-

cises are a way of highlighting what is most critical in each module, so that if they miss a particular point, the exercise helps direct them to re-learn an important part. Collect the tests and place in a folder for privacy.

- Activate learning through use of a learning circle or other 'warm-up' exercise.
- Present the power point presentation and experiential exercises.
- Hand out the Post-test. Collect the tests and place in a folder for privacy.
- Pass out the Training Evaluation and place in folder/envelope when complete.
- Pass out any handouts you have
- Thank the participants as they leave

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### Modifications for non-English-speaking staff

The primary language for some participants in your learning sessions may not be English. Facilitators should actively seek the assistance of bilingual staff to facilitate participation by non-English speaking staff if there are no translated materials available. In addition, facilitators will want to be creative in expanding ways to communicate. One obvious example would be to demonstrate rather than simply describe skills or ways of interacting with residents. Some modules will lend themselves better than others to demonstration.

The Internet can be a wonderful resource for finding supplemental materials that have already been translated. You will find many federal resources have been translated into Spanish. The National Institute for Mental Health website is one place to start.

([www.nimh.nih.gov/health/publications/](http://www.nimh.nih.gov/health/publications/))

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# MODULE I: Welcome to OASIS

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## The Changing Face Of Long-Term Care Who's Who And What's What

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### Description

This session provides an overview of OASIS and of the residents typically encountered in the long-term care setting. The learning activities emphasize the importance of addressing common misconceptions about people with neuropsychiatric disorders and confronting one's own biases and attitudes.

Persons with long term care needs - whether residing in a facility or on their own- have the same basic needs we all have. These needs tend to be somewhat hierarchical (ranging from the most basic biological needs (life-sustaining) to the creative and symbolic (life-defining). They are also dynamic. Meaning they are in flux. Changing. Evolving.

Persons with long term care needs - whether residing in a facility or on their own- have personal resources as well as needs. This is true of person with dementia, traumatic brain injuries and serious mental illness. When strengths are not recognized and supported, residents typically become stuck or may regress to a lower level of function.

#### **Note well:**

This emphasis on basic human needs underlies the entire curriculum. It is especially important that they are made explicit during this initial session. You can do this by paraphrasing them in your opening remarks and by spending some time coming up with examples of how differing levels of need are uniquely impacted by being in a nursing home.

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### Goals

- Increase ability to work effectively with all residents
- Increase comfort in working effectively with all residents
- Increase confidence in abilities to work with all residents

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## Objectives

At the end of this Module I, participants will be able to:

- Describe OASIS
- Discuss why it is better to focus on the person and not his or her disease
- Discuss the experience of wearing a label
- Describe basic human needs
- Discuss some common experiences of individuals residing in long term care

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## Methods

- Goal setting
- Activating learning
  - Media exercise (10 minutes)
- Experiential exercises
  - Look at Me video (10 minutes)
  - Loss exercise (8-10 minutes)
  - The Power of Labels (10-15 minutes)
- Discussion
- Lecture (PowerPoint) in two parts
  - OASIS (10 -15 minutes)
  - Who's Who (15 -20 minutes)

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## Materials needed

- 1 LCD projector (or other A/V medium for lecture, DVD)
- 2 Large Labels/Signage to be worn around the neck
- 3 Learning folders to be used throughout the training
- 4 Handouts
- 5 PowerPoint
- 6 Extra blank paper and pens, pencils
- 7 Recovery article (to be read between sessions if interested)

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## Format

Begin with a brief overview of the purpose of this training, define the goals and objectives of module I, and set out the plan for achieving them. The facilitator asks each participant to write down one personal learning objective for the session. (This can also be done in advance).

Then, **EITHER** hand out the pre-test and explain that unlike many tests, this one is designed to show how much participants know –as well as what they don't know **OR** select one of the questions for discussion in a learning circle.

This module contains 4 exercises; it is recommended that the facilitator use at least three of them. This keeps participants engaged and underscores the importance of their active participation

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## Exercises

### Media exercise

After the tests are completed or discussion ended, ask participants to take out a piece of paper and write down as many stories (from newspaper articles, movies, plays or books) about aging, mental illness, substance abuse as s/he possibly can. Allow about 5 minutes. Then ask participants to put a plus or minus sign next to each selection depending on whether or not they think the story conveys a mostly positive or negative image of the older person or person with a mental illness. Ask for a show of hands as to how many had more stories with (-) signs. In a learning circle, discuss how these and other media images might affect one's view of and attitude toward older people and those with mental illness or substance abuse.

Then, using the included PowerPoint, begin the lecture, which should last no more than 20 minutes (including completing the Loss exercise).

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### Loss Exercise

During the PowerPoint presentation on loss, the facilitator conducts a loss exercise.

Participants are asked to write down the 10 things they most value in life. "Things" could be people, objects, or abstractions like health, freedom and so forth. When they've finished, the facilitator then says, "now cross off two items; you'll never have those again". After a pause, the facilitator then says, "now cross off three more". After a pause, the facilitator asks participants how they are feeling. Likely responses are 'angry', 'frustrated', 'sad'. After this brief period of reflection, the facilitator says "now cross off three more; those three are also gone for good". Participants should now be down to two items and the facilitator tells participants to choose between the two. At this point, it is not uncommon for participants to refuse. Some may put down their pens or pencils in disgust or anger or sadness. The facilitator will want to comment, that this exercise mimics the arbitrariness of loss that residents who come into long-term care frequently feel on admission. Ask participants to discuss their reactions at their tables. After about 5 minutes, resume the lecture.

## Power of Labels Exercise OR Look at Me Video

At the end of the lecture, the facilitator then conducts the power of labels exercise or shows the Look at Me Video.

Facilities may wish to consider the use of “labels are for jars” competition between units. Directions for this exercise can be found in the supplemental activities thumb drive.

Before the group disperses, the facilitator recommends some between session learning activities (paying attention to media and do and don'ts of meeting basic human needs) and reminds the group of the date and time of the next meeting.

[Author's note: I have had no feedback on whether or not any facilities have succeeded in implementing this suggestion. None of the original OASIS sites adopted the practice of between session readings due to concerns about placing unrealistic expectation on staff].

The facilitator also reminds participants that the OASIS champions will be available to answer questions on the units and to hear from participants about any OASIS “ah ha” moments.

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**Module I:****Pre-test or Discussion**

1. What comes to mind when you think of an oasis?

2. What do we mean by excess disability?

True or False? (Check all the true statements.)

3. Person-centered care is care that

puts the person in the center and the family in the background

centers on the person not disease

centers on strengths as well as needs

builds natural supports

4. People in the nursing home who have dementia

are rarely able to do anything for themselves

have memory problems but the rest of their brain function is OK

don't need to come to care planning meetings

5. Creating excess disability causes

more work for staff

poorer quality of life for residents

low self-esteem

6. Basic human needs include:

the need for love

the need for privacy

the need for sex

7. When individuals with schizophrenia are having a bad day

\_\_\_it is usually because they haven't taken their medication

\_\_\_it could be for any reason

\_\_\_it is usually because of their mental illness

RECOMMENDATION: (Use to lead a group discussion at the beginning of Module I rather than as a written test; can also be adapted for use with a learning circle)

Name:

Today's date:

# Module I: Welcome to OASIS

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## The Changing Face of Long-Term Care: Who's Who and What's What

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Lecture

Introduction

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### What is OASIS?

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disability or health care need. The goal of the curriculum is to help create a safe, secure environment geared toward successful outcomes. This includes improved functional status. OASIS addresses challenging behaviors by focusing on understanding and addressing residents' unmet needs. This goes a long way towards improving quality of life, reducing overreliance on unnecessary medications and preventing excess disability.

What is excess disability? Excess disability refers to the loss of ability to function due to factors other than those due to the disorder itself (dementia, schizophrenia or traumatic brain injury). Why focus on excess disability?

**Excess disability both increases the amount of care required and diminishes the quality of life for the resident.**

Excess disability is common in facilities with many younger people with psychiatric disabilities. Excess disability results in poorer quality of life. Excess disability increases demands on staff. Concentrating on what a person can do, rather than on what they can't do, can prevent excess disability. Building on what a person can still do results in better adjustment to the environment. Building on what a person can still do improves life satisfaction for residents and staff. Building on what a person can still do reduces burden for already busy caregivers.

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Staffs learn best if OASIS helps do the job.

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**What will we learn?**

The OASIS curriculum has 4 modules

In Module I we take a step back and ask: Who are the individuals residing in our homes? What needs and strengths might they hold in common? How can we create the kind of neighborhoods residents want to live in and we want to work in?

In Module II: We look more closely at person-centered and resident-directed care in relation to dementia and mental illness. We learn about the recovery movement in mental health and how it might impact care planning.

Module III dives into the challenge of distressing behaviors and helps staff understand what we mean by the statement all behavior is communication. It provides tools for asking: what is this resident trying to tell us and how should we respond?

Module IV: This module emphasizes institutional practices that support personhood and deal with crises and challenging behaviors by preventing them from occurring in the first place.

When you complete this entire curriculum, you will have the knowledge, skills and attitude to:

- Provide person-centered support and care to a broad range of residents;
- Maintain safety and security for all residents as well as yourselves;
- Help all residents obtain the highest practicable quality of life

#### Expected outcomes

If OASIS succeeds, your facility will show

- Higher rates of consumer satisfaction when surveyed
- Higher rates of staff satisfaction when surveyed
- Fewer resident incidents
- Reduced staff turnover
- Reduction in inappropriate use of antipsychotics
- Institutional practices reflective of culture change in care, workplace and environment

We all get set in our ways. In some ways, the more experience we have and the more we already know the harder it may be to think in new ways. Use this learning activity to re-think some ideas you have about young and old, about people with and without mental illness, with and without dementia. This will help you confront your biases and attitudes. In this first session, the goal is not to list signs and symptoms, but to really get you to think about how you think about the people you serve.

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#### Media exercise/Discussion

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#### Lecture resumes

#### Who's Who

Why we say the face of long-term care is changing.

Twenty-five years ago, policy makers had a goal of getting people with serious mental illness out of hospitals and into the community. They pictured a system that would have a range of options for care. Instead, there was no place for many of the discharged patients to go. Many such persons now find their way into nursing homes.

At the same time, frail disabled older adults with less complex needs who used to live in nursing homes now prefer to stay in their own homes. Adults with dementia are becoming the typical nursing home resident.

What people want from a nursing home is also changing. There is a move to more individualized care planning, to improve not just quality of care but also quality of life, and to create homes that feel more like homes and less like hospitals. You'll sometimes hear this movement described as "culture change".

One aspect of culture change is person-centered care. Sometimes it is called resident-directed care. Here is a simple definition for now: Person-centered care means paying attention to the unique needs, wishes and hopes at each developmental stage of the lifespan. Person-centered care is a continuing process of listening, trying things, seeing how they work and changing things as needed.

So, long-term care facilities are now home to many different people. Young adults with complex medical and neuropsychiatric needs due to brain injuries or serious and persistent mental illness live alongside older adults with challenging behavioral syndromes associated with dementia. Persons of all ages with mixed disabilities may stay for a short time or a lifetime.

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### What people in long-term care have in common

Persons with long-term care needs – whether they live in a facility or on their own - have the same basic needs we all have. These needs range from the most basic biological needs for food, water and shelter to the need to be creative and feel fulfilled. These needs are also dynamic. This means they change and grow.

A psychologist named Maslow called these the hierarchy of needs. Another psychologist called Kitwood called them essentials for well-being. Whatever we call them, we all have them and living in a nursing home uniquely impacts them. Persons with long-term care needs – whether they live in a facility or on their own - have personal strengths as well as needs. This is true of person with dementia, traumatic brain injuries and serious mental illness. Residents can

become stuck or may go back to a lower level of function when strengths are not recognized and supported.

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## Who's Who

First and foremost people who live in long-term care are people. This may seem an obvious or even a silly thing to say. But think how often you describe people as diseases: the schizophrenic, the diabetic, the alcoholic, the Alzheimer's resident or the bipolar.

What's important to remember about people who live in long-term care is that they have or have had a life beyond the nursing home. They have stories. They have stories of success, of failure, of loss, of trauma, of dreams - just like you and me. Knowing these stories helps us give better care because it allows us to focus on the person and their strengths as well as their needs.

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## Risk and Loss

One of the key themes in a group living situation is the sense of loss. We do not have time to explore this in any detail today, but think about what it means to become psychiatrically or otherwise disabled and to be required to move into a group setting that may or may not be of one's choosing. Entering long-term care typically represents a loss of health, of independence in activities of daily living, of home and personal belongings, of control and decision-making. Some may also have lost loved ones. In traditional nursing homes, moving into the nursing home also meant the loss of identity, of choice, of autonomy and privacy. Even when desired there is a loss of lifestyle, of independence, of control and of others. Any loss of independence or control -- qualities highly valued in our society -- can be a blow to a person's self-esteem. It's difficult for most people who have been self-sufficient to accept increased dependency.

We now know that protecting autonomy, honoring identity, maximizing choice and respecting privacy are critical for good care and a high quality of life. The regulations also require you to do so.

What is the difference between autonomy and independence? We tend to think of these two words as meaning the same thing but they are very different and the difference is important. Autonomy means the right to choose. It means calling the shots in one's own life. You will also hear this referred to as the right to self-determination. It is considered a fundamental human right and protected by the constitution. It includes the right to take risks and to make so-called "bad" decisions.

Independence means the ability to do something by one's self. A person can be totally dependent and still have autonomy. Can you think of an example? Christopher Reeves is one person who comes to mind: he was totally dependent on others to meet his most basic needs and yet clearly called the shots in his life right up until the time of his death.

Now let's try to put ourselves in the shoes of those who live in long term care

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## LOSS EXERCISE/Discussion

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### Basic human needs

People who live in long-term care also have the same basic human needs we all have. The drive to get these needs met is no different in you, the person with schizophrenia or the person with dementia. What may be different is how we each go about and, how successful we are, in getting those needs met. Having a chronic illness or living in long-term care effects an individual's ability to meet these needs.

Many psychologists have tried to answer the question of what makes us tick. The names of these psychologists are not that important but their ideas are very important.

One you may have heard of is a man named Maslow. He said all human have certain needs in common and these needs motivate our thinking and behaving. He believed these needs were arranged like a pyramid and that we need a solid base if we want to try to meet all our different needs. In other words, individuals who are cold, hungry, in pain, thirsty, afraid, feel like they don't belong cannot really feel good about themselves or work towards a sense of purpose and meaning. Think about this for yourself: if you are very, very hungry or sitting in a very cold classroom you will find your self thinking about when the lunch break is or how to get warm -or get out! - instead of paying attention to the facilitator.

#### Biological or physiological needs

These are the most basic of human needs. They consist of needs for oxygen, food, water, and a relatively constant body temperature. They are considered the strongest needs because if a person were deprived of everything, these would be the first that a person would need to satisfy. Living in a long-term care setting can have a positive or negative impact on these needs.

### Safety Needs

This refers to a need for a sense of safety and security. It includes the need for personal space and privacy. Living in a long-term care setting can have a negative or positive impact on these needs. Little private space, frequent intrusions by staff or other residents, entering rooms without knocking, touching without asking permission, moving residents' belongings are all examples of negative effects that can be easily reversed.

In the long term care setting, most individuals experience some undermining of their basic needs on an almost daily basis whenever the call bell is not answered, a door is opened without knocking, a person who can't dress themselves, is left without a sweater. This is especially true for so-called "behavior residents" who -for whatever reason- are no longer able to ask for what they need directly and must express themselves through their behavior.

### Needs for Love, Affection and Belongingness

Maslow believed we all try to overcome feelings of loneliness and separateness. Dr. Bill Thomas, who created the Eden Alternative and Green House projects, called loneliness and boredom the scourge of nursing homes.

This involves both giving and receiving love, affection and the sense of belonging. In long-term care, meaningful communication and connection with friends, neighbors and family may be lost or lessened. It can be difficult to make new relationships in the long-term care setting, especially when there are major differences in cognitive abilities and sensory impairments.

### Needs for Esteem

When esteem needs are satisfied, the person feels self-confident and valuable as a person in the world. When these needs are frustrated, the person feels inferior, weak, helpless and worthless. In the long-term care setting, staff can have a positive or negative effect on a person's self-esteem. Calling a person by their preferred name, avoiding the use of labels, asking a person about his or her life and accomplishments, looking for opportunities for a person to make his or her own choices are all ways of supporting an individual's need for esteem and self-respect.

### Needs for Self-Actualization

Think about yourself. What makes you "most you." That's what we mean by self-actualization. It's about the need to have an identity and showing what we can do. This means being able to take risks and fail as well as succeed.

Now let's step again into the shoes of those who live in long term care.

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The Power of Labels exercise or Look at Me video

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## HANDOUTS

### Do's and Don'ts Related to Basic Human Needs: Creating OASIS Moments.

Here are some ways to support residents in their pursuit of a better quality of life – whatever their disability. **Ask staff to add ideas/examples to the list.**

#### DO

- Talk to residents about who they are and what matters to them
- Identify an individual's preferences on admission and honor them
- Learn as much as you can about who a person is from his or her family if he or she can't tell you
- Ask individuals by what name they like to be called and use it
- Create a welcoming environment on entry (admission) and in care conferences
- Orient new residents to the facility so they feel less anxious
- Introduce new residents to other residents and staff
- Create opportunities for choice
- Make sure residents have what they want to eat and drink
- Respect privacy - Knock on doors before entering rooms
- Answer call bells –even if it's not “your” resident or “your” job
- Wear a name tag that is easy to see and read
- Help *with* ADLs rather than just doing ADLS *for* the resident
- Create care plans to support basic human needs as well as the nursing care of a health problem.
- Include residents in their care planning conferences
- Make a commitment to learn one new fact about your residents or co-workers everyday.

#### DON'T

- Use labels or identify people by their disease
- Do something for a person if he or she can do it for him-or herself - even if it takes longer
- Pressure residents to hurry when they're doing something for themselves
- Touch individuals or their belongings without permission

Champions should refer to this list when out on the units and remain on the “lookout” for small successes and examples to reinforce

# Module I: Post-Test

A. True or False? (Check all the true statements.)

1. Person-centered care is care that

builds on natural supports, such as family and friends

centers on the person not the disease

centers on strengths as well as needs

2. People in the nursing home who have dementia

are rarely able to do anything for themselves

have problems with many aspects of brain function

can express choices

3. Regarding basic human needs

biological needs are the most basic and the strongest when not met

all adults have a need to feel safe and secure

all adults have a need to feel a sense of belonging

4. A primary role of caregivers is

to listen to what individuals who live in long term care have to say

to get all their tasks done as fast as possible

to know their residents' diagnoses

to get to know their residents as individuals

B. Discuss the following ideas with your facilitator.

Why it is better to focus on the person and not his or her disease.

Why we say the face of long-term care is changing.

Name: \_\_\_\_\_ Today's date: \_\_\_\_\_

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# MODULE II

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## MENTAL HEALTH, RECOVERY AND STRENGTH-BASED, PERSON-CENTERED CARE

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### Overview

The session starts with a review of diagnostic categories primarily to then dispense with them! It reinforces the content of Module I (characteristic human needs) while encouraging staff to continue to examine their assumptions about the population for whom they care. Most staffs, particularly those with extensive backgrounds in mental health, are likely to hold the view that knowing a diagnosis tells them what they need to know to take care of a given individual. Nothing could be further from the truth. In fact, in our experience, those in mental health often know the least about the research on recovery in schizophrenia. Historically, individuals diagnosed with major mental illness, such as schizophrenia, were viewed as being on an inevitable downward course, with no hope of recovery. Many staff will hold this view.

This session continues to reinforce the principle that new knowledge demands new ways of providing care. This module provides an overview of the recovery movement and describes how the principles of recovery can be used to inform care planning and problem solving. This session also re-visits the concepts of person-centered and strength-based care planning and introduces a simple method for non-nursing staff, residents themselves and even families to contribute to care planning

Staff will learn not just the language of recovery and person-centered care but how to apply the principles in their everyday interactions with residents. This is important not only because regulations and the marketplace increasingly REQUIRE individualized care planning (which is one practical manifestation of both recovery and person-centered care) but because both can lead to better outcomes for both the person with schizophrenia and the person with dementia.

Be sure to familiarize yourself with the literature on recovery in schizophrenia and person-centered care planning in dementia.

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## Objectives

At the end of this module, participants will be able to:

- define recovery and person-centered care as it applies to any person of any age with any neuropsychiatric disorder
- identify a range of interventions for persons with neuropsychiatric disabilities in the long term care setting
- use a simple grid for incorporating strengths into a care plan alongside the resident's MDS triggered problems.
- discuss what it is like to stand in the shoes of someone who hears voices or is always afraid.

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## Methods

- |   |               |
|---|---------------|
| ▪ Lecture (PowerPoint)                  | 10-15 minutes |
| ▪ Sensitization exercises (3)           | 10-15 minutes |
| ▪ Discussion group                      | 10-15 minutes |
| ▪ Strength-based care exercise          | 15-20 minutes |
| ▪ Use video or case study from facility |               |

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## Materials

- Laptop/LCD Projector/DVD player and speakers
- Flip chart
- Strength-based care planning exercises (2)

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## Format

Present the brief lecture on recovery. Then complete the sensitization exercise followed by a brief discussion of the experience. Then present the remainder of the PowerPoint on person-centered care and self-advocacy and strength-based care-planning.

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## Sensitization exercises

### Exercise 1: Auditory Hallucinations

#### Overview

The purpose of this first exercises is to sensitize participants to the experience of an auditory hallucination. There are several ways to do this. Three options are presented.

#### Method

To begin, the facilitator asks if anyone can describe what hallucinations are. Hallucinations, the facilitator should explain, are a symptom of psychosis in which a person hears (auditory), sees (visual), smells (olfactory), tastes (gustatory) or feels (tactile) something that isn't there.

The facilitator then asks trainees to pair up. One person stands behind the other who should be sitting. The person standing is instructed to lean over and continually whisper something in the person's ear (such as a nonsense rhyme) and to interject it with comments about the person to whom they are speaking. For example, *"Mary had a little lamb, little lamb little lamb the lamb is white you're wearing a (color) shirt. I don't like your shoes. He followed her to school one day he's following you"*

While the partner is talking to the seated person, the facilitator also tries to get the attention of the seated person to go on with the class. The facilitator may ask the seated members questions, read something or try to elaborate about some point from the just concluded lecture. This is an attempt to simulate auditory hallucinations. This should last just about two minutes or so.

An alternative method is to divide the group into groups of three. One person, who will be "the voice" stands behind the listener and reads something to them. This can be a nonsensical script as above or something more organized. A sample script is provided below. The third person, acting as a staff person sits in front of the listener and converses as s/he might with a person s/he is meeting for the first time.

A third approach is to have the listener sit and listen to an iPod while the person in the staff role tries to engage with them.

Allow participants a few minutes to discuss their reactions before moving on to the second exercise.

#### Sample script for "the voice" during the hallucinations exercise.

*"Don't trust him/her. Don't trust anyone here. (let your voice fade to a whisper). People will hurt you. Yes, they will. Your family is in on it. They're plotting against you (then say the person's name a few times in a soft voice). This is a bad place. (make some low sounds: humming or clicking noises, then be silent for 3 or 4 seconds). This is a very bad place (be silent again for a second or two). You are so stupid. Why are you letting them keep you here? You're a bad person. That's why you have to stay in a bad place. (Silence). You're not a bad person. You're a good person. You don't need to be here. Go home, home, home. Home is where the hearth is. What is the matter with you? Why do you keep sitting there. S/he is full of s\*\*\*. S/he doesn't know you. S/he he doesn't like you. We like you. Run, run, run. See Jack run. (Silence) Go, go, go.*

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## Exercise 2: Paranoia

The purpose of this exercise is to sensitize staff to the experience of paranoia.

### Method

Staff is asked to close their eyes and recall the most frightening movie they have ever seen. To help stimulate their memories, the facilitator may wish to offer the most frightening movie s/he has ever seen as an example.

The facilitator should then “walk” participants through the experience with the following script: *Remember how you felt going to the movie. You probably had certain expectations; that is, that you would be frightened. You may have heard from someone else that it was scary or you may have guessed it from the title or from knowing about the director’s reputation. Recall how you felt in the early part of the movie, knowing that something bad was bound to happen. Recall how you started picking up little clues from what was said or the way someone was acting or from the music. Recall how as the clues mounted, the tension also mounted and the music began building to a crescendo. You were likely tense, on the edge of your seat, waiting for something to happen. Then it did and the tension was released, only to begin again in the next scene.*

*Now, keeping your eyes closed, try to remember the feeling just before something happened. This will give you a little idea of what the paranoid person feels all the time: on constant alert, looking for clues, waiting for something bad to happen, knowing the worst will happen but not when or from where or perpetrated by whom. Since much of the paranoia is delusional, nothing ever really happens and the tension doesn’t get discharged. There is only enduring apprehension.*

*Now open your eyes and let’s discuss your experience.*

The facilitator will want to read this script in a low, but audible voice, preferably walking around the room to add to the experience of not knowing where the sound is coming from. Frequently remind the participants to keep their eyes closed. If any participant looks unduly frightened, add a reassuring remark that you’re not going to touch anyone or sneak up on them, you’re just going to walk around the room.

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## Exercise 3

### Words/Colors

Using the slides embedded in the power point, have participants read aloud together the words on slide one as quickly as they can. Then show the second slide and have them “read” or say the color of the word rather than the word as written.

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**Exercise 4****Seeing strengths exercises (2) Mary and Suzanne**

Depending on the level of sophistication/experience of the participants, you may wish to skip the written exercise (very easy) and begin with the video.

Distribute this paragraph or read aloud.

Pick out 5 of Mary's strengths in the following paragraph (or select a resident from the facility whose strengths are less obvious)

Mary is a 70-year-old **woman** who was admitted to your center from **home** where she lived with her **family**. She had a stroke and cannot use her right arm or leg. She is **alert** and **oriented** and **loves to socialize**. She becomes anxious if she cannot see her clock. Her **family visits** daily and brings her the newspaper which she **enjoys doing the crossword puzzle** in it.

How did you do? In order to know the strengths of your residents, you must get to know all about your residents. You can do this through conversation with the resident or their family, and/or reading the social service and activity assessments. The best way is through personal conversations.

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**Suzanne video/Small group exercise**

Read the background on Suzanne's story. Tell participants that they are to listen closely to hear what Suzanne says about her needs and wants and to jot down notes as they watch. Then they should complete the strength grid in a small group.

# Module II: Pre-Test

1. True or False? (Check all the true statements.)

People with schizophrenia can recover

If people with schizophrenia would take their medication regularly they would not have outbursts

People with schizophrenia need other people to make good decisions for them.

Residents in the same stage of dementia are all more or less alike.

Who the resident IS has more influence on their behavior than whatever their diagnosis is

2. What is strength-based care? Why is it considered better?

Name: \_\_\_\_\_ Today's date \_\_\_\_\_

RECOMMENDATION: (Use to lead a group discussion at the beginning of Module II rather than as a written test; can also be adapted for use with a learning circle)

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## Module II: Mental health, recovery and strength-based, person-centered care

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### Lecture (script)

#### Introduction

In this module you will learn how to build on a person's cognitive and daily living skills when making a care plan. Remember, unlike traditional maintenance or "preventing deterioration" approaches to care, strength-based care is preferred because it:

- Improves life satisfaction for residents and staff; that is, it makes people feel better about themselves and each other
- Reduces burden for already busy caregivers; that is, it will actually make your job easier in the long run;
- Helps residents adjust to their new home
- Creates an atmosphere of hope

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### Goals:

- Increase ability to use recovery principles
- Increase ability to work effectively with all residents
- Increase comfort in working effectively with all residents
- Increase confidence in abilities to work with all residents

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### Objectives

At the end of this module, you will be able to:

- Define recovery and person-centered care as it applies to any person of any age with any neuropsychiatric disorder
- Identify a range of interventions for persons with psychiatric disabilities in the long term care setting
- Use a simple strength-based care planning tool
- Discuss what it is like to stand in the shoes of someone who hears voices or is always afraid

As in our first session, strength-based care requires that we focus on who a person is, not just on what he or she has. However, it also helps to know how particular disorders, especially those affecting thinking, feeling and communicating can create particular challenges or barriers to reaching one's goals.

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## Commonly encountered disabilities

Overall, the most common mental health disorders encountered in long-term care are anxiety and depression. Of the more serious and persistent mental illnesses, the most commonly encountered are schizophrenia, bipolar disorder, severe personality disorders and substance abuse disorders. It is not necessary to learn about these in detail but it may be helpful to know about the what it might be like to have these disorders; it will help you “stand in the shoes of those who have these conditions.”

Traumatic brain injuries or closed head injuries and dementia syndromes are even more common but for historical reasons are not usually referred to as psychiatric disorders or mental illnesses. This was back when we split the mind and the brain! Terms like “organic” or “organic brain syndrome” are now considered very outdated even though some people continue to use them.

### Schizophrenia

Schizophrenia typically begins in young adult hood but may develop in later life. People with schizophrenia typically have the following unique characteristics and challenges in long term care.

People with schizophrenia experience psychosis. This means they may hear voices, see things others cannot see and believe things for which this is no rational basis and which others do not share. Hearing things, seeing things, feeling things on your skin, smelling odors or tasting something that isn't there are all called hallucinations. Having a fixed, false belief about something is called a delusion.

People with schizophrenia experience difficulty organizing their thoughts and communicating logically.

### **Contrary to popular belief, people with schizophrenia recover.**

In the past, individuals diagnosed with major mental illness, such as schizophrenia, were viewed as being on an inevitable downward course, with no hope of recovery.

We now know this is wrong. For one, not all people with schizophrenia are alike. In several long-term follow-up studies published between 1960 and 1991, almost 1/3 of patients clinically recovered. At least half showed a social recovery. Our tendency to group all people with the disorder as “schizophrenics” and to expect them to have the same needs is outmoded.

One of the biggest human challenges faced by people with schizophrenia in long term care is that staff have a tendency to see *everything* that person does as related to or caused by the mental illness. Remember, people with mental illness have good days and have bad days, just like you and me. Another common burden placed on people with mental illness is that staff tends to overemphasize the importance of medication as a way of altering behavior. Imagine what it would be like if every time you were sad or upset about something in your life, (maybe a fight with your friend, death of a pet or a loved one or maybe you just woke up ‘on the wrong side of the bed’), and your friends or families asked “did you take your meds today?” instead of “what’s wrong?” While medications can be useful in recovery, **taking medications should never been seen as a goal unto itself. Taking medication is a means to reaching one’s goals, not an end.**

In addition, people with schizophrenia were seen as unable to make their own decisions and in need of professionals to protect and make decisions for them. This has been especially true in institutional settings.

Over-protection and restricting choice have negative effects. It contributes to the kind of excess disability we talked about in session I. Reclaiming the right to make mistakes – like the rest of us- is what Patricia Deegan calls “the dignity of risk and the right to failure”.

Residents with serious mental illness may:

- be anxious around other people
- be unsure around other people
- have difficulty organizing thoughts
- have trouble paying attention

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## Experiential exercise Hallucinations/Paranoia (see above)

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### Developmental Disabilities

Developmental disabilities refer to a diverse group of severe chronic conditions due to mental and/or physical impairments. People with developmental disabilities have problems with language, mobility, learning, self-help, and independent living.

A common developmental disability is Down’s syndrome. People with Down’s syndrome used to die in young adulthood but now tend to live much longer. With longer lives, they are also at risk for developing Alzheimer’s disease. Alzheimer’s Disease may look different from Alzheimer’s disease in a person without Down’s syndrome.

People with Down's syndrome and Alzheimer's disease may

- Show changes in personality before changes in memory
- Have long periods of inactivity or indifference
- Develop seizures
- Lose daily living skills

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## Dementia

Dementia is not a single disease but a syndrome. Dementia has many causes. It affects people in late life. While we tend to think of dementia as a memory disorder, it actually effects many aspects of brain function such as language, abstract thinking, problem-solving, arithmetic, orientation, planning, recognition of people and places and expression of emotions.

Residents who have dementia may

- Have difficulty remembering or communicating
- Have difficulty saying what they want to say
- Understanding what you're asking

In traditional care models, there is frequently little effort made to help persons with dementia maintain their highest level of function. Persons with dementias are also seen as being on such an inevitable downward course that their remaining abilities and personhood are often overlooked. The focus of care has been on having a clear and accurate understanding of the impairment, in order to chart decline overtime. In the new culture of dementia care, a it is considered important to have a clear and accurate understanding of a person's background, abilities, tastes, interests and values. There are now very good evidence-based practices derived from this new way of thinking. Our new knowledge demands new models. You'll hear more about this in the next module on behavior.

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## Traumatic Brain Injury

An injury to the brain caused by external trauma to the head or violent movement of the head. The most common causes are falls, especially among seniors and young children; car accidents and violence. Traumatic brain injuries are very common among veterans of the Iraq and Afghanistan wars.

Residents who have traumatic brain injuries may

- process information more slowly
- have trouble concentrating

- have difficulty solving problems or planning ahead

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## Experiential exercise Words / Colors

Standing in the shoes of someone with a brain injury

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### Building relationships

As staff for people with psychiatric and other disabilities who are living in nursing homes, your role is more than a doer of tasks. Your role is to really SEE the individuals for whom you are caring. To TALK with them as individuals. To LISTEN to their stories. It is about building a relationship. You will see in Module III that this will go a long way towards addressing distressing behaviors.

Individuals living in long term care hold onto many life-long abilities even when they need a significant amount of care by the time they enter a nursing facility. Residents with the same diagnosis, or who appear at first glance to be functioning at the same "stage" or "phase", will demonstrate a wide range of retained abilities.

WHO the PERSON is exerts more influence on behavior than what he or she HAS. It is important, therefore, that the resident be encouraged to perform those actions and activities which rely on retained abilities, also called STRENGTHS, for as long as possible to optimize independence.

In the introduction to OASIS, we presented the idea of excess disability. Excess disability is more likely to occur when we neglect an individual's strengths.

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## What is Recovery?

Here are some simple definitions given by both professionals and by individuals with major mental illness who are in recovery.

Recovery is

- The ability to have hope
- The ability to trust my own thoughts
- The ability to enjoy the environment
- The act of gaining and taking back hope, personal identity and abilities

In short, recovery is a way of living to make the most out of life. What is most important for staff to show is

- A belief in the person's capacity to recover
- A willingness to be clear, honest and informative
- Desire to learn from each individual what she or he feels, thinks and wants
- An ability to use this information in the manner most helpful to that person

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### What is person-centered care?

The ideas behind person-centered care are simple. Person-centered care is based on the beliefs that:

- Every person in long term care has strengths, gifts, and contributions to offer
- Every person in long term care has hopes, dreams and desires
- Every person in long term care has some ability to express preferences and to make choices
- Person-centered care puts the individual squarely in the driver's seat and for this reason is sometimes referred to person-directed care

Another way to put it is this: Person-centered care

- Centers on the person not disease
- Centers on the person's strengths not losses
- Shifts perspective on quality to individual
- Encourages relationships
- Puts equal weight on the person's psychological and social needs

Whatever the cause of the disability, knowing your resident will allow you to find ways to make the disorder less of an obstacle. As you get to know the resident better, you will get to know the resident's likes and dislikes and abilities in different settings. You will come to know what situation and what other people bring out the best in the resident and which do not. Each interaction reveals something about the resident's personality, such as his/her sense of humor. This builds a relationship with the resident as he/she is now, instead of being preoccupied with the loss of any prior capabilities.

Each resident is unique in his/her response to the challenge of having a brain disorder, whether it is Alzheimer's Disease, schizophrenia or a traumatic brain injury. Each has had a different social and individual history that causes them to cope in different ways. **Every relationship that develops between a resident and a staff person will also be built on the different life experiences of the resident.**

By calling attention to the resident's intact abilities, the staff and others can help ease an individual's grief and frustration over lost abilities. **Think of the resident as someone that has valuable life experiences to share.**

**The resident should be the source of information about himself.** It is important to obtain information about the resident from the resident. This will provide a glimpse of the resident's preferred view of his/her life and how it affects him/her. So few people really take the time to learn the resident's perspective on his life, that many times the resident stops trying to give it.

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## Problems and Strengths

The Resident Assessment Protocol (RAP) triggers from the Minimum Data Set (MDS) assessment are stated in "problem" mode. Identifying resident strengths in the care plan may help reduce the severity, frequency or intensity of an identified problem. In so doing, our aim is to improve functioning, rather than to prevent deterioration.

**This strength-based approach makes it possible to collaborate with the resident's wish to retain independence.** Helping a resident use his/her natural skills of competent behaviors gives a sense of mastery of the environment.

**Strength-Based Care Planning starts with getting to know the person.** This includes getting to know what makes the resident feel good about him or herself and what gives the resident pleasure. The interdisciplinary team uses this information to develop a complete picture of each resident's unique abilities, strengths, needs and wants.

If some of his/her abilities are not being supported in daily care, the team will want to change the care plan so that the resident's strengths are being used. This will help prevent excess disability.

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## Seeing strengths exercises (2) Mary and Suzanne

## Additional Notes

Most facilitators will be familiar with hallucinations and you will likely have your own ways of describing them. Here's one description staff with little or no experience in mental health have found helpful.

### What are hallucinations?

An hallucination is when you hear something when no one is speaking. When you see something that isn't there. When you taste something when there is nothing in your mouth. When you feel something crawling on your skin when there is nothing there, and when you smell something that nobody else can smell. In other words, hallucinations are disturbed perceptions: You see, smell, hear, taste, feel something that isn't there. That's one example of a break with reality about the external world.

For people with schizophrenia, the most common kind of hallucination is auditory. They hear things. They hear people speaking when no one is speaking. For people with substance problems, particularly during withdrawal, they are more likely to see things than to hear things and to feel things crawling on their skin.

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Handout: More OASIS Moments

Questions to explore on the unit:

What common interests or experiences do you share?

What experiences has this person had that you are interested in finding out about?

What talents or personality traits does the resident have that you enjoy?

What makes the resident happy?

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Try to learn the resident's "language"

What meanings are behind the resident's most common words?

What is the resident trying to tell you? Try to understand and validate the resident's non-verbal communication, also.

Check with the resident to clarify any communication you don't understand e.g., "Is this what you meant? I'd like to understand how you feel about this."

What is important to the resident in his/her life today?

What is the resident feeling today?

What makes the resident feel important in this setting?

What would the resident like to do that he/she is not doing now?

Is it possible to support the resident in this activity, or in something similar to it, that would give the resident a feeling of satisfaction?

# Module II: Post-test

1. True or False? (Check all the true statements.)

People with schizophrenia can recover

People with schizophrenia need other people to make good decisions for them.

Residents in the same stage of dementia are all more or less alike.

The diagnosis is the most important influence on behavior

2. How does strength-based care planning begin?

3. Define recovery in your own words

Name: \_\_\_\_\_ Date \_\_\_\_\_

RECOMMENDATION: (Use to lead a group discussion at the end of Module II rather than as a written test; can also be adapted for use with a learning circle)

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# MODULE III: All About BEHAVIOR

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## Description

No topic in long-term care has received as much attention as the topic of “difficult or problem behaviors”. Sometimes labeled challenging, agitated or disruptive, these behaviors pose challenges for everyone. Disruptive behaviors upset care routines and cause stress. Disruptive behaviors frighten other residents and may put residents and staff alike at risk of physical harm. Disruptive behaviors may trigger fear, anger and guilt in staff.

The preceding two modules have set the stage for a shift to a new paradigm of care that actually can prevent some of these challenges from arising in the first place; and secondly, to address them non-pharmacologically when they do arise.

Module III completes the shift by assisting staff to first understand why challenging or disruptive behaviors occur and then to help build confidence in their ability to communicate with someone who is withdrawn or non-communicative; is suspicious, mistrustful or paranoid; has delusions or hallucinations; is threatening or aggressive. This module gives staff the tools needed to recognize and address unmet needs thus minimizing the occurrence of disruptive behaviors. Finally it teaches staff effective techniques for de-escalating situations **without the use of prn or standing antipsychotic medications.**

This module changed titles countless times during the design of this curriculum. Originally it was entitled “Challenging encounters” to remind the facilitator and learner that the challenge in challenging behaviors is in the encounter. To put it differently, it is often assumed that when there is a “problem” it is the resident’s behavior not ours that is causing the problem. **The approach in this module is predicated on the belief that the best approach to resolving difficult situations requires more understanding than managing.** “Challenging encounters” failed to convey the disruptive aspect of some of the most challenging encounters. Finally, I elected to use no modifiers and to just call the module “all about behavior” to set a more neutral stage.

Open this session with a discussion of the dilemma of describing behaviors in a way that doesn't simply label the resident and remind participants of the power of labels or "Look at Me" exercise from Module I.

Module III is divided into two parts and facilitators are encouraged to present the two parts a week or more apart (though this has not been proven to be critical).

Be sure to familiarize yourself with the work of Jiska Cohen-Mansfield so that you can describe it to staff and to read this entire section on Module III prior to the learning sessions.

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## Objectives

At the end of Part A, staff will be able to

- Explain the basic principles of communication
- Describe how all behaviors are communications
- Identify common environmental and physical problems that are expressed through behavior
- Describe a strategy for dealing with any challenging behavior

At the end of Part B, staff will be able to:

- explain the usual meaning of aggression, agitation, wandering and isolation
- describe strategies for dealing with the resident who is...
  - ...combative, threatening, kicking, hitting
  - ...screaming, yelling, banging, clapping
  - ...withdrawn or non-communicative

---

## Methods

- Lecture/PowerPoint (50 minutes) (in two parts)
- Just in time learning circles on unit (5-10 Minutes)
- Videos
- Exercises
  - Part A
    - Identifying non-verbal communication (10-15 minutes)
    - Active listening exercise/Discussion (5-10 minutes)
  - Part B What is this person trying to tell us
    - Behavior exercises (25-30 minutes)
    - Behaviors forms

Most facilities have some method for documenting and tracking disruptive behaviors. These forms should be used as a supplement to whatever forms are currently in use.

If no system currently exists, facilitators may wish to recommend the use of this form. As training tools, they provide a convenient process for walking participants through an assessment of behaviors as an unmet need.

# Module III: Pre-Test

A. True or False? (Check all the true statements)

Labeling residents as "behavior residents" is a good approach to care: it tells us what to expect.

Disruptive behaviors are usually an attempt to communicate an unmet need.

Behaviors in dementia don't really mean anything because people with dementia don't know what they're doing.

Words like agitation, aggression, problem behaviors, and disruptive behaviors all mean more or less the same thing.

Body language and tone of voice are more important than words in communication. Together they make up about 90% of how we communicate.

B. List some common environmental contributors to disruptive behaviors

Name: \_\_\_\_\_ Date \_\_\_\_\_

RECOMMENDATION: (Use to lead a group discussion at the beginning of Module III rather than as a written test; can also be adapted for use with a learning circle)

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# Module III All About Behaviors

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## Lecture (script)

### Overview

#### One problem with problem behaviors

Different terms and vocabulary are used to describe the many varied behaviors. Terms like "agitation", "disruptive behavior", "wandering", "searching", "verbally aggressive," and "regressed" are just some of the terms used by various care providers, researchers, clinicians, regulators and family members. These terms lack agreed-upon meanings and are often used interchangeably. You may think others use a term the same way you do when they do not. In this module, we will use the terms challenging and disruptive behaviors interchangeably when describing the big picture. We will use more precise descriptions when talking about commonly encountered behavioral communications in the long-term care setting.

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#### What you will learn from Module III

This module is designed to help you understand why challenging behaviors occur; to help you feel confident in your ability to communicate with someone who is threatening or aggressive; is withdrawn or non-communicative; is suspicious, mistrustful or paranoid; has delusions or hallucinations. You will acquire the tools you need to recognize and address unmet needs and to de-escalate challenging situations.

One common but not very effective approach to dealing with such behaviors is simply to label the resident or the behavior. This approach mostly reflects the caregivers' view of how the behavior affects them. It doesn't identify what is at the root of the behavior from the resident's point of view or suggest what to do about it. Caregivers usually assume that when disruptive behaviors become a problem, it is the resident's behavior not ours that is causing the problem.

This module also addresses delirium. This life-threatening syndrome is a medical emergency and all staff must be able to recognize the early warning signs. Delirium is commonly encountered in both hospital and long-term care settings especially in elderly individuals with cognitive impairment. You will

learn the known risk factors for developing delirium, how to decrease that risk, how to recognize delirium and what to do about it.

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## Goals

- Increase ability to work effectively with all residents
- Increase comfort in working effectively with all residents
- Increase confidence in abilities to work with all residents

---

## Objectives

At the end of Part A, you will be able to

- Explain what we mean by the statement: All behavior is communication
- List common environmental, interpersonal and physical problems that are expressed through behavior
- Describe a strategy for dealing with any challenging behavior

At the end of Part B, you will be able to:

- Explain the usual meaning of aggression, agitation, wandering and isolation
- Describe strategies for dealing with the resident who:
  - ...Is combative, threatening, kicking, hitting
  - ...Is screaming, yelling, banging, clapping
  - ...Is withdrawn or non-communicative

---

## Part A: Communication

### Lecture continued

### Overview

Because understanding the resident's communication is the key to preventing and addressing challenging behaviors, we begin this module with a review of key communication principles.

Did you know that only about 10% of what we communicate is actually through our words or speech? Tone of voice and body language are almost 10 X as important! This is always important to keep in mind about how we communicate but it is CRITICAL when attempting to de-escalate situations. Because we're so accustomed to "reading" faces and posture, we usually think we're pretty good at it. This deserves to be emphasized: Understanding another person's communication – whether expressed directly or indirectly –

whether through verbal, non-verbal or other behavior- requires a willingness to keep an open-mind and a wish to understand.

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### Non-verbal communication exercise/discussion: Emotions/Flash cards

The implications of good communication cannot be overemphasized. Consider every situation that can and often has gone wrong between people: poor communication of one kind or another was often responsible. Equally, anything that goes right between people is usually the result of effective, positive, and helping communication.

Communication can be complicated by many factors. Hallucinations, speech, language, cognitive and sensory deficits are fairly obvious but frequently overlooked. Cultural differences may be less obvious but no less important. Environmental noise and a lack of privacy are fairly constant obstacles in the long-term care setting that must be addressed to allow for effective communication.

The best vantage point for understanding another person's communication is to try to stand in his or her shoes. In other words, try to see the situation from another's point of view. This is not as easy as it may at first seem. If you think for a moment about the times when you have felt most frustrated talking to your supervisor, your spouse, a doctor or your child it is likely because the other person isn't getting your point of view! Standing in another's shoes requires, at least temporarily, giving up your point of view.

This first step toward enhancing communication may be taken with very little fanfare. It begins with EMPATHY, a concept at the core of effective communication. Standing in another's shoes is one way to describe empathy. Empathy is the quality of thinking and feeling about a situation from another's point of view. In the communication process, empathy means that the sender of message first considers: who is receiving my message? What is the level of understanding of the receiver? What is the sender's attitude toward the receiver and the message? What other things might the receiver have on his mind?

Remember what you learned in Module I? A key theme in long-term care is loss. Think about what it means to become psychiatrically or otherwise disabled. Think about having to move into a group setting that you may not have chosen and may not like.

Think about the loss of identity. Even if a person chooses the nursing home, there may be a sense of loss of individual identity. There is certainly a loss of lifestyle, of independence, of control and of one's natural supports.

Loss of independence or control -- qualities highly valued in our society -- can be a blow to a person's self-esteem. It's difficult for most people who have been self-sufficient to accept increased dependency.

These are the shoes to stand in while thinking about challenging behaviors.

A second element in communicating more effectively is to become more familiar with your own response to certain stress-provoking situations. Each of us, as individuals, can tolerate different situations and different amounts of stress. Further, we all define our DIS-stressors differently. It takes a fair amount of honesty and self-study to recognize and acknowledge those situations. We must then take steps to either change the way in which we react, change the situation, or know when to react.

Listening is the third area in which skill building will bring quick rewards. We all start out with some degree of listening ability. The challenge is to move from a passive to a more active role so that our listening becomes more effective. It is probably the single most useful skill to have. It is also an easy skill to learn. It starts with checking your own assumptions about what the other person is communicating.

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## Active listening exercise/Discussion

### Lecture resumes

To summarize, in order to communicate effectively, the knowledge we need is SELF-KNOWLEDGE, the skill we need is ACTIVE LISTENING and the attitude we need is EMPATHY.

The emotional state can also complicate communication. It is easy to see how the resident's anger, anxiety, depression or paranoia could become obstacles to effective communication. But what about your own?

You may have to deal with such difficult questions as "Why should I go on?" "I wish I were dead" "I hate it here" "everybody here is out to get me" and so on. Sometimes we feel inadequate to deal with those kinds of feelings. Sometimes we are trying to adjust to our own feelings about mental illness, about old age, about trauma, about substance users, or about having our best efforts ignored or rejected. Sometimes we see only minimal progress, and sometimes we see none.

External factors can also contribute to communication difficulties. These may be present in any human interaction, but they are particularly strong in nursing homes and adult homes where the residents may have little if any private or

personal space, where the needs of the many tend to overshadow the needs of the individual, where the “rules” of the house may often seem quite arbitrary and where the resident does not feel empowered to make decisions. In the case of those living in a home not of their choosing or receiving treatment involuntarily, you can see that the resident actually has lost some decision-making power.

What does this all have to do with challenging behaviors?

With respect to challenging behaviors, this can be especially important because so often there is a tendency just to want it to stop, rather than to be understood. With respect to well-established patterns of behavior, keeping an open mind and an attitude of curiosity are important because there is a tendency to dismiss some behaviors with a resigned “that’s just the way he is”. This can lead to missed communications, needs being unmet and later escalation of behavior.

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## Behavior as communication

We behave - or act - in an attempt to signal a feeling or to meet some basic human need for comfort, control, security or affection. Often times we ask indirectly - or not all! - hoping another person will simply “know” - or should know - what we want!

To put it another way, we communicate to effect a change in our environment: we either want something to start happening that isn’t or we want to stop something from happening that we find undesirable. The first question about behavior we always ask is: what is this person trying to tell us? Is there a pattern? When, where and with whom does the behavior happen? Is this behavior new? Is it familiar? Never dismiss a resident’s behavior as “he’s just like that” - use the familiarity as a clue to what it means.

Generally, the next step in understanding behavior as communication involves asking: if the person is telling me something needs to change, what is it? What needs to change?

Is it the environment; my behavior or attitude; the resident's behavior?

Remember: it is easier to change our own behavior than someone else’s.

It is also important to step back and ask why a challenging behavior is so often labeled a problem-rather than an attempt at problem-solving! Ask, is this behavior really a problem? If so, whose problem is it? Mine? The administrator’s? The family’s? The other residents? All of these points of view are valid, and it is important to know whose shoes you’re standing in order to come up with a

correct understanding of the communication and the right ‘solution’ to the right ‘problem’.

End the lecture by having each participant pick one resident who has challenging behaviors and ask them just to pay extra close attention for one week. When visiting the unit, ask each staff to tell you what they are seeing and ask what they think the person is trying to communicate. Select one or two examples to use during the next module.

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## Part B: Common challenging behaviors

### Overview

As we’ve been saying, over and over again, research has shown that disruptive **behaviors are usually an attempt to communicate about an unmet need or goal**. The approach to addressing disruptive behaviors in this facility is based on this research. It is based on the idea that the best approach to resolving disruptive behavior requires more understanding than modification.

Let’s see how it compares to older models.

In a traditional behavioral model, all behavior is seen in a linear, cause and effect fashion and its all about antecedents – “what happened before to trigger the behavior?” and what were the consequences? That is, did the intervention cause the behavior to stop or get worse? You will often hear this oversimplified notion expressed as “positive or negative reinforcement of behavior”. This way of looking at behavior may help explain some behavior but it is only a piece of the puzzle of uncovering a resident’s unmet need.

In OASIS, the first question we ask will be: what is this resident trying to tell me rather than how can I make him or her stop?

Let’s review the basic assumptions underlie this approach.

In a traditional medical model, behavior is seen as coming entirely or primarily as a symptom of the disease. In the case of dementia, we explain repetitive questions as a failure of the brain to process short-term memories – so the person asking doesn’t remember or “know” they just asked the question.

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### Behaviors as symptoms

The first thing to notice about this graph is how common behavioral symptoms are. Over half of all persons with Alzheimer’s disease experience depression, irritability, wandering, change in day and night rhythms and agitation.

Whether or not these behaviors become problems or are disruptive may depend largely on how staff responds. Trying to stop someone from walking about for example may lead to aggressive behavior.

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## The relationship between the brain and behavior

First, the big picture: The right side of the brain controls the left side of the body. Seeing the big picture? That's a right side of the brain job too. The right side gives us our visual memories, visuospatial relationships and self-awareness.

The left side of the brain controls the right side of the body and is the more logical side. It is the side we draw on for language, verbal memory, and putting information in the right order (called sequencing) The left side also regulates our emotions.

We can also connect brain and function by looking at the different lobes. In this module, we most interested in five of them: the frontal, parietal, temporal, hippocampus and amygdala. Why these five? Because each plays a key role in helping us understand behaviors associated with traumatic brain injuries, schizophrenia and dementias.

### Frontal lobe

The frontal lobe is the executive suite of the brain: It is the lobe for problem solving, analyzing complex situations, making and carrying out decisions. It is the last lobe to develop and is not fully developed until our mid-twenties. The frontal lobes allow us to be flexible in our thinking, to initiate action, to monitor our own behavior and to stop us from behaving in unacceptable ways.

When the frontal lobes are damaged –as they often are in schizophrenia, in brain injuries and in Alzheimer's disease, individuals lose the ability to plan and initiate complicated activities. That's why it becomes important to break processes into simple steps. This loss of processing skills makes reasoning with people who have frontal lobe deficits virtually impossible. People with traumatic brain injuries are not being stubborn; their brains just aren't healthy enough to carry out the complex processes that logic demands. People with schizophrenia may find it hard to stay motivated or to initiate action

### Temporal lobe

The temporal plays a key role in memory, language and high-level sensory processing, like understanding speech. Problems in the temporal lobe start to cause problems recalling words. Naming things becomes particularly difficult, to the point where, eventually, the speech of someone with Alzheimer's becomes devoid of specific nouns. Problems in the temporal lobe are responsible

for hallucinations in individuals with schizophrenia. In the middle and later stages of Alzheimer's disease some individuals may also experience hallucinations.

#### Parietal lobe

The parietal lobe helps us orient our bodies in space and decipher where and what things are. When Alzheimer's disease affects the parietal lobe, individuals become lost and disoriented, even in familiar settings. They may also mix up objects, thinking that a waste can is a toilet.

#### Hippocampus

The hippocampus takes our immediate thoughts and impressions and turns them into memories. Alzheimer's disease attacks the hippocampus first, so short-term memory is the first thing to fail. Eventually, new memories become impossible to make and learning is a thing of the past. Without knowing what just happened, it's difficult for people to judge things like time, place and what's going on around them. This is why conversation with residents with Alzheimer's disease should focus on the past, where the memories are more accessible and don't rely on new learning.

#### Amygdala

The amygdala regulates basic emotions such as fear, anger and craving and is affected quite early in Alzheimer's. An individual may display surprising behaviors such as apathy, paranoia, emotional outbursts and inappropriate sexual advances. Unprovoked hostility and anxiousness might appear completely out-of-the-blue.

**You might begin to ask yourself how we can ever hope to help residents whose brains have been so affected by their different disorders. You may be thinking: if outbursts are just the amygdala firing how can I intervene? Don't we just have to take it? NO. The medical model is also a piece of the puzzle, but doesn't tell the whole story.**

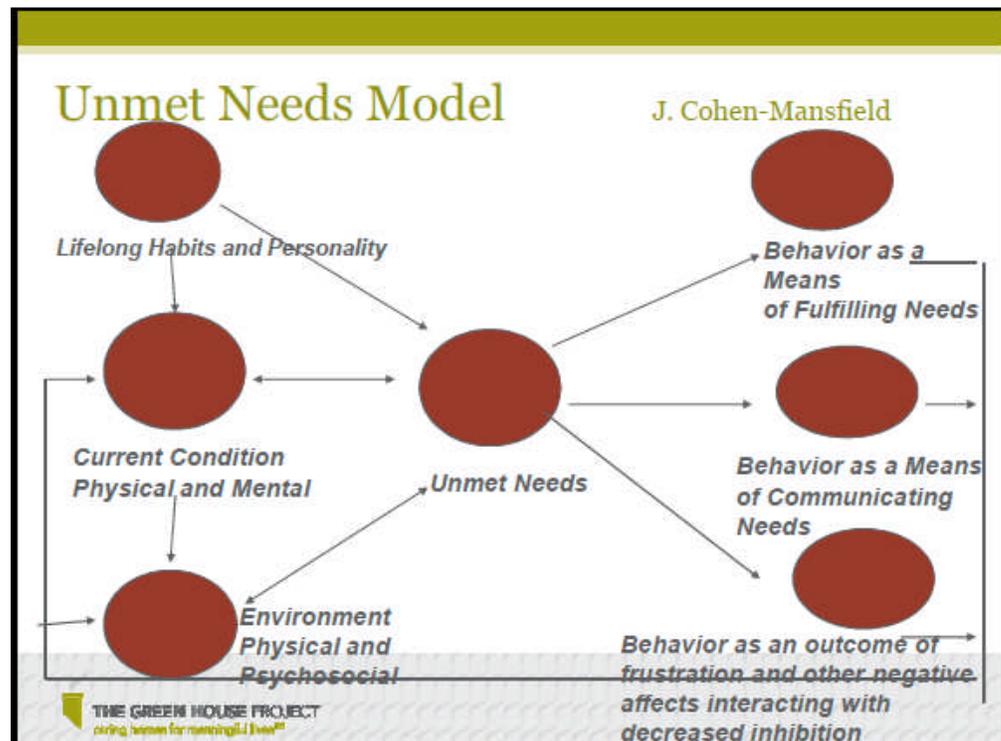
Recall a time you had a really bad day. Perhaps you know what triggered it, but perhaps not. You just felt moody. Out of sorts. Irritable. Had a short fuse. Took someone's head off. That was a day when your amygdala had a minor malfunction. It's likely you coped with it more or less effectively. You probably figured out somehow to minimize the potential damage to your relationships or your job. Maybe you went for a run. Maybe you listened to music. Maybe you wanted to just be left alone. But you dealt with it. Using what works best for you, using your strengths. That's what person-centered, strength-based care is all about.

When a person with Alzheimer's disease experiences a blast from the amygdala, she or he can't recall what would help. But if staff knows the person, staff can intervene until the outburst passes. Maybe this person dealt with moodiness by listening to music, maybe by walking, petting the cat. When taking a strength-based history, finding out about previous effective coping strategies can help you select the right intervention.

## Understanding Behavior as Communication of Unmet need

The OASIS curriculum is built on over 25 years of clinical experience of its author and validated in large measure by the research of Jiska Cohen-Mansfield.

Here's how all the pieces come together: Lifelong habits, personality, current circumstances all having a bearing on what a person needs and how those needs are met and communicated.



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Here's how can we apply this to our day-to day work:

To review: First, all behavior has meaning. All behavior is an attempt to communicate. It may not be immediately apparent, even to the person who is behaving in a challenging way.

Second, many people, including ourselves, do not always ask directly for what we want or need. Often, what is described as a problem behavior is actually a problem-solving behavior. It is a misdirected attempt to get some basic human need met.

Third, it is easier to change our behavior than to change someone else's.

So let's now apply the behavior-as-communication model to commonly encountered behaviors. Take wandering for example. What is a person who is wandering or walking about trying to say?

Generally, walking about seems to say "I'm bored" or "I'm lost" or "I'm looking for someone". Purposeful walking, as in towards the exit everyday at shift change, would seem to communicate, "I want out".

Next, what need is not being met? What needs to change? If the resident is looking for stimulation, then finding other sources of pleasure and interest may be desirable. If the person appears to enjoy walking about, then perhaps nothing needs to change. On the other hand, if the person is keen on leaving the facility, the care team needs to ask what would help the resident adjust to the nursing home OR ask the family if another setting would better meet his or her needs. Perhaps a less restrictive or more familiar setting would be more welcome.

The next question might be: is walking about a problem? If so, whose? If the fear is that the person will fall, then the problem to be addressed is not walking about but the risk of falling. In this instance, the team would want to focus any intervention on the fall risk: making sure the halls are free of clutter, pathways are lit at night, resident's shoes are sturdy and fit, medications are not contributing to fall risk, and so forth. If the fear is the resident will leave the building, get lost, hit by a car or exposed to bad weather, then the problem is not the walking but the environment. The real problem in this instance is not the walking but exiting without anyone's knowledge and being unable to return or stay safe. Changes to the environment to make it more safe is more appropriate

than trying to stop a person from walking about. Walking is actually a good way to preserve muscle tone and reduce the risk of pressure ulcers.

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## Isolation

Individuals who isolate themselves do so for a variety of reasons. The communication seems pretty simple: I want to be left alone. The challenge to the rest of us is to try and understand why.

Ask the participants to come up with some ideas about why people stay by themselves.

Is the individual staying in his room because he is afraid? He might like to join in but suffers from social phobia or other form of anxiety. Or does the fear run deeper? Is the person suffering from paranoid ideas or delusions?

Does the individual stay in his or her room because he or she is hard of hearing and finds it too frustrating to be in a group and unable to hear?

Is the individual staying in his or her room to conceal the use of alcohol or other drugs?

Or does the person simply like to be alone? As a culture, we tend to overvalue extroverts and socializing. While it is true that forming social connections is associated with better mental health, it is not true that the social connections must always be in a group.

Always find out if the person would like to be less isolated before trying to correct a problem that may not exist! How to find out? ASK them.

Now let's apply what we've learned to some other common behaviors. Keep these questions in mind as we go through them:

- What is this person trying to tell me? What is the need? What needs to change?
- Is there a problem? Whose problem is it?
- If I see any of these behaviors, what should I do?

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## Agitation

This word is too imprecise to use for care planning so get in the habit of describing what you mean. What I mean by agitation is any behavior that is self-

referred. That is, it calls attention to the person and seems to be saying HEY! Look at me. I need something. HELP. This includes yelling, calling out, slapping a table, clapping loudly, screaming, slapping thighs, pacing in front of the nursing station and so on.

Do any one of these behaviors and you will see what I mean. People will look at you. They will ask if you're OK.

Screaming, yelling and calling out are sometimes dismissed as "wanting attention". You're right. But why dismiss such a clear communication? The person who is screaming does want attention: he or she is trying to tell you something is wrong.

These behaviors are common in residents with dementia, delirium, stroke, developmental disability, brain injury and agitated depression. What these residents have in common are brain disorders, which result in language deficits, memory problems, decreased self-awareness, dependence on others and often decreased mobility.

Some common triggers include:

- Noisy environment
- Change of shift, overhead pagers, chair alarms are common sources of noise
- Not enough stimulation
- Pain
- Constipation
- Discomfort
- Infection
- Drugs
- Hearing loss
- Is the person cold? Hot? Thirsty? Hungry? Lonely? Anxious?

#### Akathisia

One particular kind of agitation, caused by certain kinds of medications bears special mention. This is the problem of akathisia. At one time it was fairly common in persons with major mental illness on certain medication.

Akathisia is a drug-induced motor restlessness that is characterized by the inability to stand or sit still. The individual may pace or rock back and forth on the soles of his feet. It is caused most commonly by the older anti-psychotics like haldol and prolixin, but can also be caused by high doses of the so-called SSRIs, which you know as the "prozac" type drugs.

*If you see this behavior, report it immediately to the nurse. It is a very uncomfortable side effect.*

#### How to respond?

The job of every member of the team is to:

- Make sense of the communication
- Offer reassurance
- Address the underlying problem
- Look for a pattern to uncover a continuously unmet need

What if you can't make sense of the communication? That's the time to call a care-planning meeting and to brainstorm with the team, resident and the resident's family to figure out the communication. Ask: What do we know? What do we need to find out? Is there a pattern? If you don't know, monitor the behavior for a week or until the pattern becomes clear.

It can be discouraging and frustrating to respond to a resident who is screaming day after day and to try everything you can think of to find out what she or he wants and to have the screaming persist.

**What is most important is not to dismiss behavior as "that's just the way he is."** *Remember, all behavior has meaning.*

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Lost watch Video simulation/ Seeing with new eyes

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#### Aggression

This word is also too imprecise to use for care planning so get in the habit of describing what you mean. What I mean by aggression is any behavior that is other-referred. Aggressive behaviors include kicking, hitting, pinching, biting, swearing and threatening statements. This behavior communicates STOP. Go away. Something is wrong with you. Leave me alone. Recall Dr. Cohen-Mansfield's research: These behaviors are most commonly in response to an invasion of personal space or when the resident is in close physical contact as in bathing.

Most aggression is fear-based. Aggressive behaviors are seen in individuals with dementia, delirium, stroke, paranoia, delusions of persecution, develop-

mental disability, brain injury, intoxication. What these individuals have in common is that they have lost the ability to SAY something is wrong and/or have lost the ability to control their behavior because of loss of inhibition.

#### Common causes include

- Fear
- Anxiety
- Frustration
- Medications
- Sensory loss
- Crowded or noisy environments
- Invasions of personal space
- New people on the floor
- Abrupt, tense or impatient staff

#### What is the best way to respond?

The job of every member of the team is to

- Make sense of the communication
- Reduce fear and reasons to fear
- Speak in a low, slow calm voice
- Offer reassurance
- Address the underlying problem
- Stop doing what you're doing
- Back away
- Look for a pattern to prevent triggering the behavior in the future

What if you can't make sense of the communication? That's the time to call a care planning meeting and to brainstorm with the team, resident and the resident's family to figure out the communication. Ask: What do we know? What do we need to find out? Is there a pattern? If you don't know, monitor the behavior for a week or until the pattern becomes clear. Ask: what strengths does the resident have? How can we best engage his abilities to minimize the intrusions into his space?

As with the agitated behaviors discussed above, it can be discouraging and frustrating to respond to a resident who is combative during care day after day and to try everything you can think of to find out what she or he needs and to have the combativeness persist.

What is most important is not to dismiss behavior as "that's just the way he is." *Remember, all behavior has meaning.*

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My Chair! Video simulation/Applying new seeing skill

# Module III: Post-Test

1. True or False? (Check all the true statements)

Most agitated behaviors are trying to communicate unmet needs

It is easier to change our behavior than someone else's behavior.

Behaviors such as pacing, dressing and undressing or trying to get to a different place usually communicate a need for stimulation rather than discomfort.

Behaviors such as complaining, constant requests for attention, screaming often occur when residents are alone and usually communicate discomfort, pain or unmet social needs.

2. What is the first question to ask about a behavior?

3. What is akathisia?

Name: \_\_\_\_\_ Date \_\_\_\_\_

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# MODULE IV

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## INTERVENTIONS

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### Introduction

Many curricula designed to address disruptive behaviors tend to focus on the physical skills staff may need to prevent injury to themselves or others. OASIS training focuses on creating a safe, person-centered environment in order to AVOID dangerous situations, just as training on fire safety emphasizes preventing fires rather than how to extinguish them. *A safe environment helps meet the human need for a sense of safety and security, reduces staff and resident injuries and helps to prevent the emergence of aggressive and agitated behavior as defined by Cohen and associates.*

This cannot be over emphasized.

Depending on staff's experience, you may wish to begin this module by discussing any recent experiences on the unit that resulted in, or nearly resulted in an assault.

The purpose of this discussion is to allow staff to vent and to hear from one another how similar situations might be avoided in the future. It is also a time to learn whether staff hold certain attitudes that may interfere with learning. For instance, many staff in long term care, especially those with a lot of experience or who have a background in state hospital service, may believe that getting hit is "just part of the job". Nothing could be further from the truth! This attitude may need to be addressed by the facilitator to remove it as a barrier to learning.

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### Objectives

At the end of this module staff will be able to

- Implement changes to the environment that increase safety
- Recognize and address common antecedents to assaultive behavior
- Reduce the risk of injury in a dangerous situation

- Recognize the early warning signs of delirium and explain why it is important to recognize the early warning signs of delirium

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## Methods

- Lecture/Power point (20 minutes)
- Small group work: Creating a safe, person-centered environment  
Basic human needs worksheet worksheet  
This exercise involves brainstorming about creating a person-centered environment in the facility where participants actually work. This is not meant to be an abstract consideration of factors but rather how to make and keep your facility safe.
- Discussion
- Video simulations (30 minutes)
  - Repetitive questions
  - Leaving
  - Bathing without a battle

You may wish to have two facilitators –or one facilitator and a volunteer from the participant group act out common scenarios and de-escalation techniques or utilize standardized videos from the STAR video trainings by Linda Teri.

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## Materials needed

- LCD Projector/DVD player
- Flipchart
- Basic Human needs worksheets

# Module IV: Pre-Test

1. True or False? (Check all the true statements)

\_\_\_ A crisis holds both danger and opportunity.

\_\_\_ The best crisis intervention is prevention.

\_\_\_ Good sleep hygiene involves establishing a daily ritual of sleeping and waking times that match the facility's regular schedule.

\_\_\_ Identifying antecedents to a particular resident's disruptive behavior is the first step in preventing a potentially harmful behavior from happening

\_\_\_ Always TELL the agitated resident exactly what to do: For example, you might say:

'You need to go to your room now and calm down'.

2. List some common antecedents or triggers to aggressive behaviors.

Name: \_\_\_\_\_ Date \_\_\_\_\_

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# Module V: Intervention

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## Overview

Chinese pictograms for the word crisis include the symbols for danger and opportunity. This well captures the nature of crisis. Thus, if an incident of potentially serious or serious self-harm or assault does occur, it is crucial that a debriefing follow immediately in order to analyze how a similar situations can be avoided in the future.

There is no practical way to teach techniques for handling every conceivable emergency or crisis situation. OASIS training focuses on creating a safe environment in order to AVOID dangerous situations, just as training on fire safety emphasizes preventing fires rather than how to extinguish them. A safe environment helps meet the human need for a sense of safety and security, reduces staff and resident injuries and helps to prevent the emergence of aggressive and agitated behavior as defined by Cohen and associates.

Nevertheless, we recognize that despite staff efforts at prevention and early intervention in managing disruptive behaviors, potentially dangerous situations may sometimes occur. This module prepares staff to deal with these situations in a way that minimizes the risk of harm to themselves and to the residents.

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## What you will learn

This module covers how to create a non-triggering environment, recognizing common antecedents to assaultive behaviors, de-escalation strategies and how to protect yourself and residents. Some environmental modifications may require significant re-design of a given physical environment. However, you should be able to adopt many of the recommended practices within any given physical environment.

You will also learn the known risk factors for developing delirium, how to decrease that risk, how to recognize delirium and what to do about it.

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## Goals

To enable staff to create and maintain in a safe environment in order to:

- Reduce number of resident to staff and resident to resident assaults
- Reduce incidence of injury
- Reduce the incidence of delirium

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## Objectives

At the end of this module you will be able to

- Implement changes to the environment that increase safety
- Recognize and address common antecedents to assaultive behavior
- Reduce the risk of injury in a dangerous situation
- Explain why it is important to recognize the early warning signs of delirium
- Recognize the early warning signs of delirium

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## Creating and maintaining a safe environment

### Reducing unnecessary stimulation

- Eliminate or reduce use of overhead paging systems
- Control noise levels by monitoring television and radio volume; for hearing impaired residents, provide earphone amplifiers rather than turning up the set
- Use soft but adequate lighting
- Control noise levels by monitoring staff conversation levels, especially during change of shift
- Provide common quiet space, especially as alternative space during large group activities
- Practice speaking in normal conversation tones at all times

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## Meeting Basic Human Needs work groups/discussion

Facilitator invites each small group to report on a given section. These can also be followed up on in an ongoing way on the units

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## Lecture resumes

Evidence supports environmental modifications aimed at:

- Creating home-like environments
- Reducing unnecessary stimulation
- Structuring activities to reduce boredom
- Supporting normal sleep/wake cycles

Creating a home-like environment may include:

- Providing freedom to go outdoors unescorted by securing outdoor walking paths with fences or walls or
- Creating more opportunities for escorted walking by utilizing all staff as explorer (i.e., walking,) companions
- Using decorative objects to enhance common living space.

Examples are:

- Posters of familiar public figures
- Pictures
- Enhance environment with elements of nature or family-like scenes.
- Recorded nature sounds
- Wall murals of forests, valleys, vistas
- Using personal objects to enhance personal living space

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## Structuring activities to reduce boredom

Idleness is a well-known contributor to boredom and agitation. Residents with neuropsychiatric disorders need assistance in structuring their days, initiating activity and remaining motivated to participate in activities. Residents are more likely to participate when these activities are pleasurable, meaningful, and individualized according to their personal interests and strengths. As with other aspects of care, strength and activity-based individualized care planning is the process for identifying these activities.

Bear in mind that many individuals with schizophrenia may not have developed skills for identifying and participating in leisure activities whereas adults who did not develop dementia until late life will have past experiences upon which to draw. Reducing boredom among individuals without developed leisure skills may require building these skills.

Structured activities include recreational activities, outdoor walks and physical exercise programs.

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### Supporting normal sleep/wake cycles

Poor sleep is a known risk factor in agitation. Getting a good night's sleep requires good sleep hygiene. Good sleep hygiene involves establishing a daily ritual of sleeping and waking times that match the residents' normal habits of sleep and waking. This intervention requires asking each person on admission what time of day they normally like to go to bed and get up and what activities they like to engage in upon arising and before going to bed. If the resident is unable to answer for him or herself, ask a family member.

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### Delirium: a special kind of agitation/This section is especially critical for nursing staff

Delirium is an *acute* change in mental status. It signals a **medical emergency**. Delirium **can worsen any underlying medical condition or even lead to death**. Delirium is often referred to as an acute confusional state.

The key features of a delirium are:

- Acute onset
- Fluctuating course
- Inattention
- Disorganized thinking
- Altered level of consciousness
- Hypervigilant, alert
- Lethargic, stupor
- Coma

**Delirium is often missed, particularly in older adults with dementia.** Sometimes, when a person is sent to the emergency from a long-term care facility with a suspected delirium, the emergency room will send the person back to the facility without even doing an appropriate work-up because the confusion is mistakenly thought to be due to age or dementia. To make the picture more complicated, age and dementia are risk factors for developing delirium.

Other residents at higher risk for developing delirium are those with sensory deficits, severe illness, fractures and polypharmacy. Polypharmacy means taking many drugs.

## CAM

You can help ensure your residents receive appropriate medical attention by using something known as the CAM –Confusion Assessment Method to detect and communicate about delirium. Dr. Sharon Inouye and colleagues developed this tool to address the failure of hospital personnel to recognize delirium. It has been well-validated and found to be reliable as a tool in hospital settings. There is no comparable tool designed just for use on long term care so for now it is the best we have.

### Ask yourself these questions:

- 1 Is there evidence of an acute change in mental status from the resident's baseline?
- 2 Did this behavior fluctuate during the past day, that is, tend to come and go or increase and decrease in severity?
- 3 Does the resident have difficulty focusing attention, for example being easily distractible, or having difficulty keeping track of what was being said? Is the resident's speech disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?
- 4 What is the person's level of consciousness?
  - Hypervigilant? Alert? Lethargic? Stuporous? Coma?
  - Is this a change from usual level of consciousness?
- 5 *If the answer to #1 and any other two questions is yes, the person probably is delirious and should be evaluated by medical personnel immediately.*

### **Drugs most commonly cause delirium.** This could be from:

- A negative drug-drug interaction
- Accidental misuse of medications
- A toxic side effect of the central nervous system
- Giving drugs like Valium
- Abruptly stopping certain drugs like alcohol or Valium type drugs
- An electrolyte imbalance caused by drugs

### **The second most common cause is infection.**

### **You can help prevent delirium from occurring by making sure residents:**

- Get a good night's sleep
- Have plenty to drink
- have access to hearing aids and eyeglasses
- Have a normal daily routine
- Ambulate daily
- Take as few medications as possible.

### **The treatment for delirium is to address the underlying cause.**

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## Recognizing common antecedents

Most of us have recognizable patterns of behavior in response to our situations. Talking loudly at dinner if we're not getting enough attention or quietly retreating to a corner of the room in uncomfortable social situations are common examples. It is usually possible to identify patterns of behavioral communication among individual residents as well. Do large groups activities prompt striking out? Does a noisy dining room prompt throwing food? Situations or events that trigger or prompt a particular response are called antecedents. We covered common antecedents to common behaviors in Module III.

Let's review them now. Facilitator picks two or three behaviors and has participants call out common triggers and writes them on a flip chart.

Identifying antecedents to a particular resident's disruptive behavior is the first step in preventing a potentially harmful behavior from happening. This information is then used to create a plan of care that helps a resident avoid these situations.

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## Predicting disruptive behaviors

Again, most of us have recognizable and predictable patterns of behavior in response to our situations. Examples might include rolling our eyes when someone says something we find absurdly obvious, swinging a leg when sitting and feeling bored or anxious or turning our backs or walking away when someone says something that hurts us or makes us angry.

These patterns both reveal something about how we are feeling and about what our next behavior might be. For example swinging a leg when bored may signal we're about to get up and walk out or turning our backs may come just before turning back around and saying something hurtful in return.

Although some residents may appear to strike out "without warning", "out of the blue" or "for no reason", most of the time residents will have given a signal or predictor of a pending or emerging disruptive behavior. Really knowing our residents as individuals, knowing their personal histories and how they typically respond to situations will help prevent more potentially dangerous behaviors from emerging. Careful analysis of situations we've failed to prevent can help us prevent the next one.

Common signals prior to striking out are finger pointing, threatening remarks, pacing, clenching jaw or fists and staring. If you see a resident who begins clenching his fists and muttering under his breath and these actions have been followed by striking out (that you've witnessed or learned by taking a careful

history on admission) then do not ignore them. Approach the resident in a calm, non-threatening manner while maintaining a safe distance and use de-escalation techniques to help the resident return to a less distressed state. Then you can address the unmet need that initiated the behavioral communication.

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## De-escalation techniques

Intervening early is more likely to be successful in preventing or minimizing injury to staff and resident alike. Intervening early requires an attitude of constant vigilance towards the environment: what is happening around you, what 'signals' are residents giving, what signals are staff giving. Is there any action you can take to increase the sense of calm and safety? Are your individual residents' needs being addressed according to their individualized plans of care?

*If a resident is displaying any behavior that signals the risk of assault, take the following steps:*

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### Take a signal breath.

What is a signal breath? A signal breath is a technique that allows you to prime your mind and body to resolve situations without confrontation. If you are upset when approaching the resident, it will only serve to make the situation worse.

Literally, stand in place, or if space permits, take a small step backward. Inhale slowly and deeply for a count of 3 seconds and then exhale just as slowly for a count of 3 seconds. Repeat the process. In under 30 seconds, you are now ready to approach the resident.

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### Approach the resident with a calm and neutral expression.

Your body language should communicate: I'm not going to hurt you. You're safe. I'm safe. Staff should make sure their shoulders are relaxed and hands are by their side. If the resident is escalated to the point where there is a greater likelihood of assault the thinking stance is preferred: one hand cupping your elbow and the other hand touching your chin. This positions your hands to block punches or kicks without looking threatening.

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### Monitor proximity

Monitor your proximity to the resident carefully, staying at a socially comfortable distance (generally 3-5 feet). Stay in the resident's visual field but approach from the side and to the front of the resident. You want to be close

enough to be heard while speaking in a soft voice but not close enough to be struck if the resident swings an arm or strikes out in anyway.

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### Make sure each of you has a way out of the area you are in.

Neither of you should be or feel backed into a corner. Sometimes the next step is to clear the area of other residents. Another staff person may help with this allowing you to focus on the resident who is signaling distress.

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### Tonality

Use a soft, neutral, calming tone of voice. Speaking almost in a whisper is sometimes helpful in evoking a similar behavior in the resident.

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### Ask – Don't Tell

Ask -DON'T TELL- the resident to walk with you to a comfortable location where you can both sit. Walk slowly. As with whispering, walking slowly is incompatible with agitation and aggression.

Ask -DON'T TELL - the resident to sit down with you to talk about what is bothering him or her. Sometimes staff act in ways that can make a situation worse. Commands and telling a person what he or she needs are associated with escalating situations. If you hear a fellow staff member saying to a resident: 'SIT' or 'You NEED to sit down now' or 'You NEED to go to your room', it will be important to review those statements during the debriefing.

*Always ASK the resident or SUGGEST the behavior you want from him or her:*

'Would you like to sit over here or by the door' 'Why don't we sit here and you can tell me what the problem is'. For residents with significant language impairment, link the words with non-threatening gestures such as pointing or slightly turning your body toward the chair or couch to indicate what you're asking.

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### Identify

With the resident, identify solutions to address the unmet need that triggered the behavioral communication.

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### Offer the solution immediately.

In many cases, a solution may be possible but was not previously offered or was delayed too long. For example, if the resident is thirsty, provide something to drink; if hungry; something to eat.

Staff sometimes voice concern that this will only “reinforce bad behavior”. This is based on a popular misperception and misapplication of behavioral modification. OASIS training starts with the assumption that behaviors are a communication. The behavior stops when the communication is understood. The behavior never starts when there is no need for the communication. Anticipating and attending to an individual’s needs is part of person-centered care planning and goes a long way towards preventing disruptive behaviors.

### Offer an interim solution.

In some case, the desired solution is not immediately available. The resident may want to go outside to smoke and the smoking policy does not allow smoking on demand. In this instance, ask the resident what he or she might like to eat, drink or do until the next smoke break and then remind him or her the time of the next break. Have alternatives on hand for those who can use them (sugar free hard suckers or candies may be an option for some). In the specific case of smoking, addressing nicotine addiction and boredom should probably be added to the residents care conference.

### Listen actively.

When a solution is not clear or available, simply listen, write it down and make a plan with the resident to address the concern at the next care planning meeting.

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### Diversion and distraction.

There may be occasions in which it is not possible to identify the unmet need. In those circumstances, it may be possible to turn the resident’s attention toward something pleasurable. The better you know your residents’ strengths and interests, the better able you will be to select a distraction that is actually likely to engage them positively.

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### Protecting yourself and others: Special circumstances

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#### Combativeness with Care

Most combativeness with care results from approaching care of residents with dementia in the traditional model: as tasks to be completed efficiently and quickly, whatever the resident’s communication. OASIS training emphasizes

preventing combativeness with care by optimally converting personal care into an activity to be enjoyed or at a minimum, into a less frightening experience for the person with dementia. If you have not previously viewed **Bathing without a Battle** by Joanne Rader, this would be a good opportunity to do so. Copies were provided to every nursing home by CMS.

Daily care needs should be addressed as part of each resident's individualized plan of care rather than as a set of institutional tasks that are done to everybody.

Approaching it from this vantage point allows you to make very specific plans about what care is given, when, by whom and under what circumstances. This prevents the need to give care to a combative resident.

The decision to approach with a second staff person must be undertaken with caution. Remember what you learned in Module III: When a resident is actively combating the staff person, the communication is clear: STOP what you are doing and back off. Most often, when a second staff person is called into the room, the situation escalates as the resident is now fighting for his or her life.

#### Biting and grabbing

Bites are obviously very serious events and are almost always avoidable.

- 1) Avoid gestures that threaten.
- 2) Never reach across a resident to provide care. Always walk to the other side.

This is always good practice but it is imperative when providing care to a resident who is known to bite or grab.

- 3) Do not attempt a single transfer of a resident who is physically agitated. Your neck and shoulder are too vulnerable to being bitten. Ensure the resident is calm prior to transfer; or, use a two person-transfer if for some reason the situation does not allow you time to help calm the resident first.

# Module V: Post-Test

1. True or False? (Check all the true statements.)

\_\_\_ A crisis holds both danger and opportunity.

\_\_\_ The best crisis intervention is prevention.

\_\_\_ Good sleep hygiene involves establishing a daily ritual of sleeping and waking times that match the facility's regular schedule.

\_\_\_ Identifying antecedents to a particular resident's disruptive behavior is the first step in preventing a potentially harmful behavior from happening

\_\_\_ Always TELL the agitated resident exactly what to do: For example, you might say:

'You need to go to your room now and calm down'.

2. List some common antecedents or triggers to aggressive behaviors.

3. List 5 de-escalation techniques

Name: \_\_\_\_\_ Date \_\_\_\_\_

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# Appendices

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## On Recovery

Joseph Calabrese and Patrick Corrigan (2005) *Beyond dementia praecox: findings from long-term follow-up studies of schizophrenia in e Recovery in Mental Illness: Broadening Our Understanding of Wellness*, Ruth O. Ralph and Patrick W. Corrigan, eds., American Psychological Association.

Calabrese and Corrigan (2005) concluded: “Each of these studies found that, rather than having a progressively deteriorating course, schizophrenia has a heterogeneous range of courses from severe cases requiring repeated or continuous hospitalization to cases in which a single illness episode is followed by complete remission of symptoms. The findings reported in these studies as a whole indicate that roughly half of the participants recovered or significantly improved over the long-term, suggesting that remission or recovery is much more common than originally thought” (p.71). The

**Burghölzli Hospital Study (Switzerland)** This cohort included both first admissions and readmissions to the hospital during 1942 and 1943. The diagnostic criteria emphasized psychotic symptomatology. The results indicated that 53% of the group participants overall and 66% of the first admission participants were judged to have recovered or be significantly improved. Fully recovered participants comprised 23% of the first-admission group and 20% of all research participants.

**The Iowa 500 Study (United States)** In the Iowa 500 study, 186 persons with schizophrenia were followed for an average of 35 years. The researchers also included a group with affective disorder and a control group of 160 surgical patients. Compared to people from the other psychiatric groups (i.e., with a diagnosis of affective or schizoaffective disorder), 46% of those people with schizophrenia had improved or recovered.

**The Bonn Hospital Study (Germany)** This study followed 502 persons with schizophrenia for an average of 22.4 years. The results were that 22% of the research participants had complete remission of symptoms, 43% had non-characteristic types of remission (defined as involving non-psychotic symptomatology, such as cognitive disturbances, lack of energy, sleep disturbances,

hypersensitivity; in regard to the latter, some patients have described this state as a type of “skinlessness”), and 35% experienced characteristic schizophrenia residual syndromes. Therefore, 65% had a more favorable outcome than would have been expected from clinical experience. In regard to social functioning, 56% of all participants were judged to be “fully recovered,” which was defined in this study as full-time employment. At the last follow-up, 13.3% were permanently hospitalized.

**The Lausanne Study (Switzerland)** This study reported the longest term follow-up of the major long-term studies. The researchers, who included Luc Ciompi, followed 289 participants for an average of 37 years and up to a total of 64 years. The results indicated that 27% reached a stabilized 5-year end state of recovery, 22% reached an end state described as “mild,” 24% were described as “moderately severe,” and 18% were judged to have a “severe” end state. There was a 14% rate of continuous hospitalization.

**The Chestnut Lodge Hospital (United States)** In this study, 446 (72%) of the persons treated between 1950 and 1975 at Chestnut Lodge psychiatric hospital in Rockville, Maryland, were followed for an average of 15 years. This site specialized in psychoanalytically-oriented long-term residential treatment. The research population consisted of persons with chronic and treatment-resistant mental illness. The researchers used a highly restrictive definition of recovery: full time employment, absence of symptomatology and need for treatment, meaningful engagement in family and social activities. The results were that two thirds (64%) of the persons with schizophrenia were judged to be chronically ill or marginally functional. One third (36%) were recovered or functioning adequately. The investigators reported that there were recoveries that included persons who had been viewed as hopeless chronic cases.

**The Vermont Longitudinal Research Project (United States)** This study, conducted by ISPS member Courtney Harding and colleagues, followed 269 persons for an average of 32 years. The participants had been ill for an average of 16 years and were hospitalized on the back wards of Vermont State Hospital for 6 years. This study is unique in that the participants were involved in an innovative rehabilitation program and were released with community supports already in place. DSM-III criteria were used. At follow-up, one half to two thirds of all participants were considered to have improved or recovered. Of the living participants with schizophrenia, 68% did not display further symptoms or signs of schizophrenia at follow-up. Almost half (45%) of the participants displayed no psychiatric symptoms at all. More than two thirds (68%) of the participants were assessed as having good functioning on the Global Assessment Scale, which provides a global measure of social and psychological functioning.

Harding, Zubin and Strauss (1987) noted that the development of chronic illness in persons with schizophrenia “may be viewed as having less to do with any inherent natural outcome of the disorder and more to do with a myriad of environmental and other psychosocial factors interacting with the person and the illness” (p. 483).

The Maine-Vermont Comparison Study ( United States) This study compared the outcomes of 269 persons with schizophrenia in Maine with the outcomes of the 269 persons in the Vermont Longitudinal Study. The average follow-up period for the Maine participants was 36 years and 32 years for the Vermont participants. The persons in the Vermont study were exposed to a model rehabilitative program organized around the goal of self-sufficiency, immediate residential and vocational placements in the community, and long-term continuity of care. The Maine participants received standard psychiatric care. Results of this study showed that the Vermont participants at follow-up were more productive, had fewer symptoms, better community adjustment, and global functioning than the Maine participants. Approximately one half (49%) of the Maine participants were rated as having good functioning on the Global Assessment Scale, the primary global measure used for both the Maine and Vermont participants. The authors suggested that it was the provision of the model rehabilitative program.

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### The World Health Organization International Study of Schizophrenia

The WHO Study of Schizophrenia is a long-term follow-up study of 14 culturally diverse, treated incidence cohorts and 4 prevalence cohorts comprising 1,633 persons diagnosed with schizophrenia and other psychotic illnesses. Global outcomes at 15 and 25 years were assessed to be favorable for greater than 50% of all participants. The researchers observed that 56% of the incidence cohort and 60% of the prevalence cohort were judged to be recovered. Those participants with a specific diagnosis of schizophrenia had a recovery rate which was close to 50%. Geographic factors were significant in terms of both symptoms and social disability. Certain research locations were associated with greater chance of recovery even in those participants with unfavorable early-onset illness courses. The course and outcome for persons diagnosed with schizophrenia were far better in the “developing countries” than for such persons in the “developed” world of Western Europe and America.

The findings of the WHO studies demonstrating better courses and outcomes for people in the developing world have been attributed to the following factors: family environment and expressed emotion; social role expectations; stigma and discrimination, etc.

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# Glossary

**acting out** - behavior that occurs as way of expressing feelings. It may be acceptable (crying when sad) or unacceptable, even destructive (throwing chairs or hitting another person when angry). It has negative connotations and is generally not the best way to describe behavior.

**active listening** - the skill of attending carefully to what another person says and conveying this attention with posture, eye contact, facial expressions, and sometimes words.

**adaptive mechanism** - coping mechanisms; learned behaviors that assist an individual to adjust to the environment.

**affect** - the pattern of observable behaviors which expresses how a person feels; in other words, how we think a person feels based on how they look, talk, and act. the outward display of a person's feelings

**ageism** - tendency to impose limitations or expectations related solely to chronological age.

**aggressive behavior** - an other-referred behavior that communicates "something is wrong with you"; used to describe violent or destructive ranging from threatening verbalizations to striking other persons or throwing objects. This behavior is often associated with anger, hostility or intense fear.

**agitation** - a self-referred behavior that communicates "something is wrong with me" "help me" examples include calling out repeatedly, shouting, screaming, clapping hands, slapping table. also used to describe anxiety associated with severe motor restlessness.

**agnosia** - literally, without knowing; loss of auditory, sensory, or visual

**akathisia** - a side effect of antipsychotic medication that is manifested by a feeling of restlessness, frequently accompanied by complaint of a twitching or crawling sensation in the muscles.

**anxiety** -feelings of apprehension

**aphasia** - loss of the ability to speak or understand language

**apathy** - a seeming lack of feelings or emotional response; apparent indifference to surroundings, circumstances, or situations

**assertiveness** - behavior that allows a person to stand up for rights, get needs met, and express feelings while not controlling or exploiting another; standing up for your rights without hurting another person

**behavior** - anything that a person does or says

**blocking** - an interruption in the flow of speech due to the intrusion of distracting thoughts

**catatonic** - a state of psychologically induced immobilization at times interrupted by episodes of extreme agitation

**catastrophic reaction** - disintegration of behaviors and thoughts, bordering on panic; induced when demands exceed one's coping capacity. This reaction is characteristic of persons with dementia when exposed to taxing situations

**clang associations** - a speech pattern characterized by rhyming.

**cognition** - the process of knowing, including judgment and awareness.

**cognitive function** - referring to processes such as remembering, thinking, perceiving, abstracting, and generalizing

**commitment** - involuntary admission in which the request for hospitalization did not originate with the patient. It is usually justified on the grounds that the patient is dangerous to self or others and needs treatment.

**compulsive behavior** - ritualistic acts, usually repetitive and purposeless in nature, used in an effort to deal with anxiety or unacceptable thoughts

**confabulation** - fabrication of stories-in response to questions about situations or events that are not recalled.

**confusion** - mental state in which a person appears bewildered and makes inappropriate statements and answers to questions.

**delirium** - an acute change in mental state characterized by sudden onset, fluctuating course, disorganized behavior and often change in consciousness; the

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person who is delirious often appears afraid, restless, confused and disoriented behavior and may experience hallucinations.

**delusion** - a fixed false belief, which has no base in reality.

**delusions of grandeur** - an exaggerated concept of one's importance, power, knowledge, or identity.

**dementia** - a progressive, deteriorating condition characterized by losses in the areas of memory, judgment, affect, orientation, and comprehension.

**disorientation** - a state in which the individual has lost the ability to recognize or determine his or her position with respect to time, place, and/or identity.

**dyskinesia** - distorted or abnormal involuntary muscle movement; tardive dyskinesia refers to late-appearing abnormal movements secondary to previous or current use of antipsychotic medication.

**dystonia** - a side effect of anti-psychotic medication that is characterized by muscle spasms, particularly of the head, neck, and tongue

**echolalia** - the repetition by a person of words addressed to him or her

**empathy** - seeing or feeling a situation the way another person sees or feels it

**etiology** - the cause of something

**formal thought disorder** - a disruption in logical, goal-directed thinking and speech; examples include, loosening of association, tangentiality (i.e., getting side-tracked, going off on a tangent), neologisms (making up new words).

**hallucination** - a sensory perception that seems real to the person despite no external stimulation of that sensory organ; more simply, hearing, seeing, feeling, tasting or smelling something that isn't there.

**manic behavior** - hyperactive behavior characterized by excessive response to stimuli, push of speech, short attention span, lack of impulse control, low frustration tolerance, inability to impose internal controls, and possibly aggressive and/or self-destructive actions.

**obsessive thoughts** - ideas that occupy the individual's time and energy to the point of interfering with daily life. the thoughts are often ruminative, deprecatory, or persecutory in nature.

**orientation** - awareness of time, place, and person.

**perception** - the process of understanding something new and then making it part of one's previous experience or knowledge; a person's awareness and identification of a person, thing or situation.

**personal space** - the physical distance people prefer to maintain in their interactions with others

**powerlessness** - perceived lack of control over events.

**pressure of speech** - an increase in the amount of spontaneous speech; rapid, loud, accelerated speech.

**psychomotor** - referring to motor actions related to cerebral activity

**psychomotor retardation** - slowing of mental and physical activity

**psychosis** - a gross impairment of reality testing; the presence of delusions or hallucinations; a state in which the individual is unable to recognize reality, communicate effectively with others, and/or exhibits regressive or bizarre behavior.

**self-concept** - the combination of beliefs and feeling one holds about oneself at a given time.

**self-esteem** - the degree to which an individual feels valued and worthwhile as a person.

**self-image** - a person's perception of self at a specific time or over a period of time.

**sensory deprivation** - insufficient sensory stimulation for a person to function.

**stereotype** - something that conforms to a fixed pattern; an oversimplified judgment or attitude about a person or group.

**stressor** - any factor that produces stress or alters the body's equilibrium.

**support system** - the people and activities that can assist a person at a time of stress.

**tardive dyskinesia** - descriptive term for abnormal movements of mouth, tongue, lips and jaw as a result of use of certain drugs, particularly antipsychotic

**thought broadcasting** - feeling that one's thoughts are being heard or projected into the environment.

**thought disorganization** - a mental condition evidenced by difficulty remembering what one is saying, confusion about time, inappropriate verbal responses, and sensory distortions.

**word salad** - a combination of words and phrases which lack meaning or coherence often seen in schizophrenia

# Additional Web Resources

[www.isps-us.org](http://www.isps-us.org)

International Society for the Psychological Treatments of Schizophrenia and other psychoses

[www.guideline.gov](http://www.guideline.gov)

National Guideline Clearinghouse on Evidence-Based Practices

[www.health.state.ny.us/diseases/conditions/dementia/edge](http://www.health.state.ny.us/diseases/conditions/dementia/edge)

EDGE project

[www.nimh.nih.gov](http://www.nimh.nih.gov)

Booklets on mental illness - 2006 publication on schizophrenia is especially worthwhile ([www.nimh.nih.gov/health/publications/schizophrenia](http://www.nimh.nih.gov/health/publications/schizophrenia))

[www.mhrecovery.org](http://www.mhrecovery.org)

Institute for Recovery and Community Integration

[www.bu.edu/cpr/](http://www.bu.edu/cpr/)

Boston University's Center for Psychiatric Rehabilitation

[www.mentalhealth.org](http://www.mentalhealth.org)

Recovering your Mental Health

[www.calculturechange.org/docs/BTF4-Regulatory\\_Compliance\\_and\\_CC-Part1.pdf](http://www.calculturechange.org/docs/BTF4-Regulatory_Compliance_and_CC-Part1.pdf)

OBRA, Compliance and Culture Change

[www.pioneernetwork.net/Data/Documents/Creating-Home-Bkgrnd-Paper.pdf](http://www.pioneernetwork.net/Data/Documents/Creating-Home-Bkgrnd-Paper.pdf)

Background paper on Creating Home in the Nursing Home Carmen S. Bowman

# Training Evaluation

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## Training Evaluation

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Title

Date

Please ✓ check each statement 5 = strongly agree 1 = strongly disagree

Objectives

5 4 3 2 1

I am better able to

I am better able to

I am able to

I am able to

Instructional Methods

5 4 3 2 1

The power-point enhanced my understanding of the material

The exercise enhanced my understanding of the material

The table-top discussion enhanced my awareness of the material

Overall Rating 5 = outstanding 1 = lousy

5 4 3 2 1

Please rate this workshop overall

Please complete the following statements

This presentation would have been better if...

As a result of today's training I plan to...

Other comments

Take a few moments with your team to consider the collective learning of this experience.

Know            Head            salient points, ideas

Feel             Heart            evoke sensitivities

Experience    Gut              build off of life experience, intuition

Do                Feet             take action

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