A PROGRAM FOR PROFESSIONAL CAREGIVERS WORKING IN ADULT DAY CARE SETTINGS

A FOUR-PART WEBINAR SERIES

Part I: DEMENTIA: It’s Not Just Alzheimer’s DISEASE (Impact for ADHC)

Part II: Working with Individuals with Agitation/Aggression

Part III: Working with Families

Part IV: Activities for the Cognitively Impaired in ADCC
Learning objectives

1. Describe 3 roles that adult day staff can assume in the lives of participants’ families.
2. Demonstrate positive interaction/communication techniques.
3. Discuss ways of responding to family needs and learn ways to effectively engage family members.
4. Examine how each attendee’s workplace can add to their family involvement program.
Family involvement is a multidimensional construct that entails visiting, socioemotional care, advocacy, and the provision of personal care (Gaugler, 2008).
WHY BOTHER?

Regulations

Benefits for centers & staff

Benefits for families

Benefits for participants
The Standards and Regulations for Licensed Adult Day Care Centers (ADCC) include the following requirements regarding participant’s family members:

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Reference</th>
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<tr>
<td>Staff are to be trained in the needs of participants’ family members</td>
<td>22 VAC 40-60-280</td>
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<tr>
<td>Admission criteria are to be discussed with family members of participants</td>
<td>22 VAC 40-60-560</td>
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<tr>
<td>Information provided by families is to be used in the assessment of</td>
<td>22 VAC 40-60-564</td>
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<td>participants</td>
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<td>Families are to be involved in developing a plan of care for participants</td>
<td>22 VAC 40-60-570</td>
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Discharge decisions are to be discussed with family members of participants (22 VAC 40-60-680)

Family members are to be notified of any significant changes in a participant’s physical and mental health, behavior and attitude, and need for additional services (22 VAC 40-60-694)
BENEFITS FOR PARTICIPANTS

- Improved function
- Continuation of family ties
- Cognitive stimulation
- Normalizing activities
- Comfort
Continuing to see the participant as a person and a member of the family

Educational opportunities – spontaneous as well as planned – about the nature of the participant’s condition and effective ways to interact with them

Preserving family memories, and adding to them

Chances to ask questions

Being able to observe and be reassured about the quality of care

Opportunities to build relationships with care providers

Participation in loved one’s direct care, if desired
**BENEFITS FOR CENTERS & STAFF**

- Responding to questions before they escalate
- Building trust with family members
- Fulfilling of regulatory requirements
- Building of favorable public opinion
- Partnering rather than confronting
- Retention of current participants and staff
- Decreased stress & increased role satisfaction
CONCERNS THAT HAVE AN IMPACT ON

FAMILIES, PARTICIPANTS, AND STAFF
Understanding ...

Community
Family
PERSPECTIVES
Participant
Staff
“If you’ve seen one family ...”

have you seen them all?”

- Family context
- Family structure
- Family history
- Family ethnicity
- Family culture
Family Roles

- Primary caregiving
- Backup caregiving
- Interpreting
- Communicating
- Deciding
The Caregiving Experience

Stress-related
illness
positive
Reward
Loss
Grief
Lifespan
Depression
satisfaction
Loneliness
Isolation
CAREGIVER EXPERIENCE

When they Struggle…
Coping with Change

Change ⇒ Stress
Stress ⇒ Coping

- Denial
- Displacement
- Intellectualization
- Projection
- Rationalization
Too Much of a Good Thing

Protection of self

Functioning in daily life

Well-being of participant

No judgment
Grieving: The Process

- Denial
- Anger
- Bargaining
- Depression
- Acceptance
Anticipatory Grief

- Loss that has not yet occurred
- Acceptance and denial
- Not universal
- Terminal diagnosis, war
- Physical symptoms
- Contact with others
No proof of death or certainty about outcome

Unresolved loss – still alive, but lost to us

“The most stressful kind of loss”

Fluctuating between hope and hopelessness

Freezes the grief process -- prevents closure

Missing the rites of passage for death
Distance

Emotional issues -> Communication

Decisions -> The participant

Caregiving
Transitions

- Admission to ADCC
- Hospitalizations
- Moves from centers to agency
- Transfer trauma if/when another level of care is needed
Community Issues

A broader focus

‘Family inclusive’ care?

More than partners in care

Meeting their needs
Assessments

What are the needs and preferences of:

- Primary caregiver
- Other adults in the family
- Children and teens

Unless there is follow-through, your time has been wasted.
Paths of Communication
Effective Communication

Only 5-7% is verbal... tone, pitch, non-verbal are key.

How good are your skills?
Barriers to Communication

- Perception/interpretation
- Generalizations/biases/prejudices
- Jumping to conclusions
- Assumptions
- Multiple meanings
- Dilution
- Message sent, but not received
Staff Issues

Values & beliefs

Stress

Emotions
More Staff Issues

- Expanded roles
- Incentives
- Training
Conflict is Inevitable

- Disagreement vs. conflict
- Expectations & promises
- Being heard
- The costs of conflict
- Negative aftermath
- Collaboration not victory
Dealing with Conflict

Empathize and validate feelings. Make confident ‘I-statements.’ Say, “I’m sorry. How can I help?” Choose a positive setting. Seek help if needed.

Participant

Reducing Stress

- Preparation
- Expectations
- Communication
- Watching for distress
- Goodbyes
- Aftermath
THE PARTICIPANT WHO IS ALONE

Not the norm but could be a possibility with the changes in family structure.
Model Programs impacting family involvement:

- The Eden Alternative
- The Family Project
- The Family Visit Education Program
- The Family Stories Workshop
- Family Involvement in Care (FIC)
- Partners in Caregiving
Your Three Roles

• Supporter
• Educator
• Facilitator
Supporter …

“… One who recognizes needs and abilities, and responds in order to strengthen another person or keep them from failing.”
Supporter:

Skills

- Validation of feelings
- Active listening
- Dealing with conflict
- Non-verbal communication
- Unconditional positive regard
- Showing respect
- Teamwork
Helpful Phrases

No confrontation, no defensiveness:

- I’m sorry.
- Tell me more ...
- What can I do to help?
- Would you sit down with me for a moment?
- I think this is important, too.
- I can do that for you.
- I’m not sure, but I’ll find out.

*Never make promises you can’t keep.*
What NOT to say ...

“This is the way we do it here.”

“Never mind.”

“I know just how you feel.”

“I’m sure your sister would help out if she could...”

“My mother’s friend takes that drug, and her doctor said...”

“Now, you shouldn’t feel that way...”
FEELINGS OF GRIEF

Appropriate way to respond would include active listening and validation of feelings rather than trying to make the person feel better.
Network of Support

The message is:

Ask for help. You deserve it.  
You are not alone.

Education is available. It gives you power.  
Support is available. It gives you strength.
Educator ...

“... One who assesses learning needs and directs the learning of another.”
Educator Skills

- Assessment of needs and abilities
- Survey of learning preferences
- Flexibility – the ‘teachable moment’
- Task breakdown
- Demonstration and prompts
  - Tact
  - Encouragement
  - Motivation
Assessment

- Surveys and assessments
- The family’s perception of what they need
- Your perception of what they need
- Their preferred way to get that information
- Direct questions: “What information would help you most right now?”
TEACHABLE MOMENTS

A time when a person is especially tuned in and motivated to learn something.
Key Topics
The Young Family Member

It is common for children to think that they have done something bad or have disappointed their loved ones when changes occur with their family member.

This is especially important for the 250,000 American children who provide hands on care for someone with dementia.

This number does not include all the other diagnoses that staff deal with on a daily basis in ADCC.
Help for Children

- Visiting
- Support
- Information
- Open-ended activity
- The needs of teens
- Books and other resources
- Group events
Facilitator

“One who stimulates actions and interactions – who connects parts and helps things along”
Facilitator: Making It Happen

Communicates with family members, their loved ones, and various staff

Contributes to organization and upkeep of materials

Organizes meeting and activity space

Shares in program scheduling and planning

‘Talks it up’ – encourages family participation and provides reminders
Facilitator Skills

- Translating family needs into programs
- Developing communication lines
- Using the communication lines
- Tending and expanding activity/learning materials
- Organizing meeting spaces and schedules
- Checking up – following through
Part 4:

Developing Your Program

- Printed philosophy
- Using model program ideas
- Options for family involvement
- Education and orientation
- Assessment of needs and preferences
- Communication between family and center
- Evaluation
Structured Family Programs

• Size doesn’t matter!
• Goals
• Framework
• Consistency
• Role definition
• Advertising
Barriers to staff promotion of family programs

- Understaffing
- Opposing staff culture (beliefs, values)
- Burn-out; decreased energy & motivation
- No involvement in program development
- Devaluation of ideas; disrespect of person or job
And the Biggest Barrier …

“This is just another lame management idea. Don’t sweat it. It’ll die just like all the others.”
Don’t Give Up!

There is no one ‘right way’ for families to respond to opportunities to participate.

Many variables and needs influence family responses:

- Needs may be met elsewhere.
- They may not be ready or able.
- We may not have provided the right options for them.
- They may simply be tired.

*Not all family members choose to be involved. That’s OK.*
Summarizing

Keys to success

Planning

Communicating

Involving and educating staff
Homework

Do your HOMEWORK!
Get others involved, develop a plan, assess and reassess.
We all want to have the best program...

YOU BE THE CHANGE YOU WANT TO SEE!