



VCU

Gerontology

School of Allied Health Professions



VIRGINIA DEPARTMENT OF
SOCIAL SERVICES

WORKING WITH FAMILIES

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A PROGRAM FOR PROFESSIONAL CAREGIVERS WORKING IN ADULT DAY CARE SETTINGS

A FOUR-PART WEBINAR SERIES

1

Part I:
D E M E N T I A :
It's Not Just
Alzheimer's DISEASE
(Impact for ADHC)

2

Part II: Working with
Individuals with
Agitation/Aggression

3

Part III: Working
with Families

4

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.

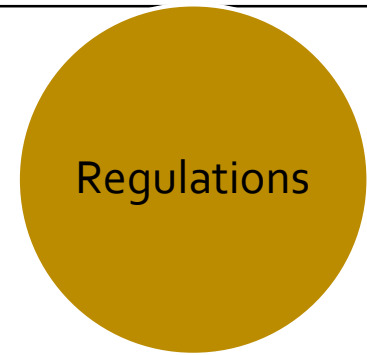
3. Discuss ways of responding to family needs and learn ways to effectively engage family members

4. Examine how each attendee's workplace can add to their family involvement program.



What is family involvement?

Family involvement is a multidimensional construct that entails visiting, socioemotional care, advocacy, and the provision of personal care (Gaugler, 2008)



**WHY
BOTHER?**



Regulations - ADCC

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

Staff are to be trained in the needs of participants' family members (22 VAC 40-60-280)

Admission criteria are to be discussed with family members of participants (22 VAC 40-60-560)

Information provided by families is to be used in the assessment of participants (22 VAC 40-60-564)

Families are to be involved in developing a plan of care for participants (22 VAC 40-60-570)

Regulations - ADCC

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

BENEFITS FOR FAMILIES

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

Staff

Family

Participant

PERSPECTIVES



**“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

Families: Emotions

Hopeful
Confused
Comforted Upset
Irritated Pleased
Embarrassed
Guilt-ridden
Depressed Frustrated
Helpless Anxious
Hopeless peace
Ashamed

The Caregiving Experience

Stress-related
illness
control
positivity
Loss
Grief
Depression
satisfaction
Loneliness
Isolation
Rewards
Changes
Life

CAREGIVER EXPERIENCE

When they Struggle...

Coping with Change

Change ⇒ Stress

Stress ⇒ Coping

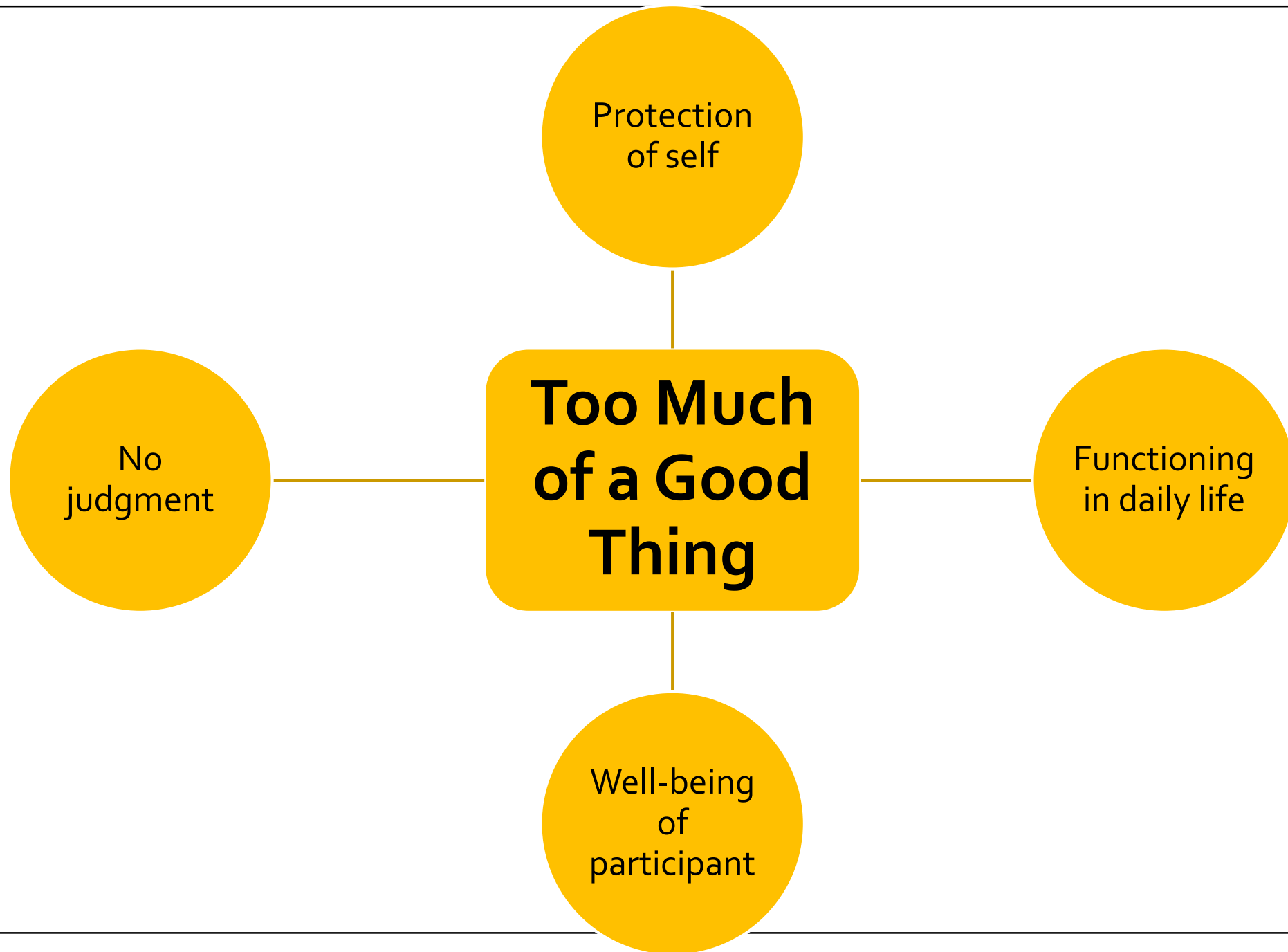
Denial

Displacement

Intellectualization

Projection

Rationalization



Grieving: The Process



Loss that
has not yet
occurred

Acceptance
and denial

Not
universal

**Anticipatory
Grief**

Terminal
diagnosis,
war

Physical
symptoms

Contact
with others

Ambiguous **LOSS**

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



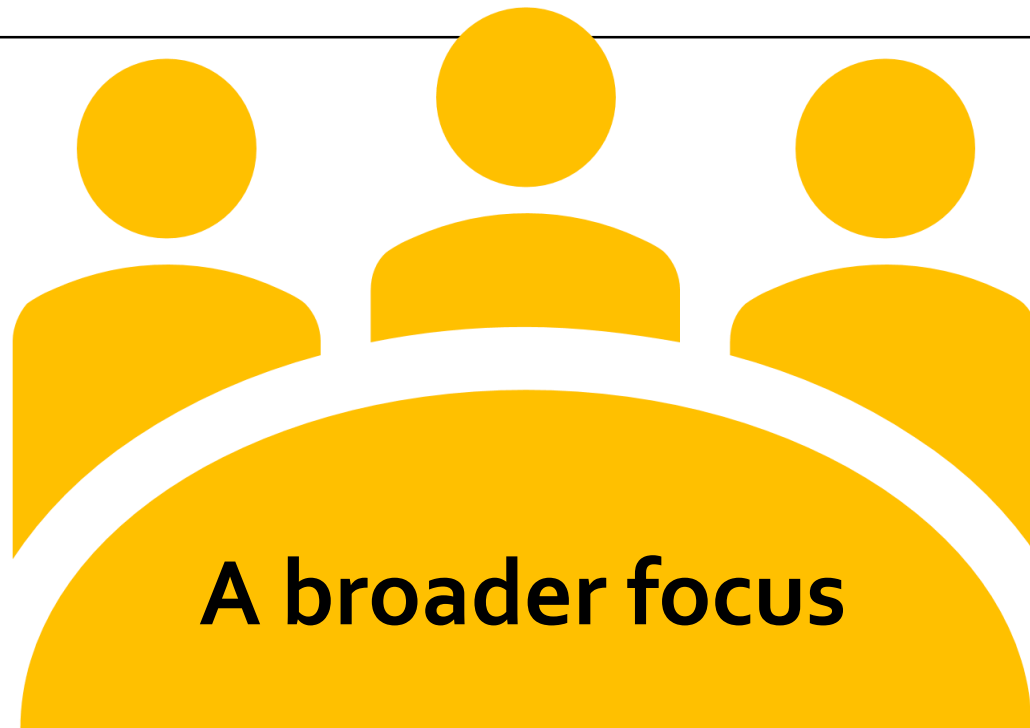
Transitions

Admission to
ADCC

Hospitalizations

Moves from
centers to
agency

Transfer trauma
if/when another
level of care is
needed



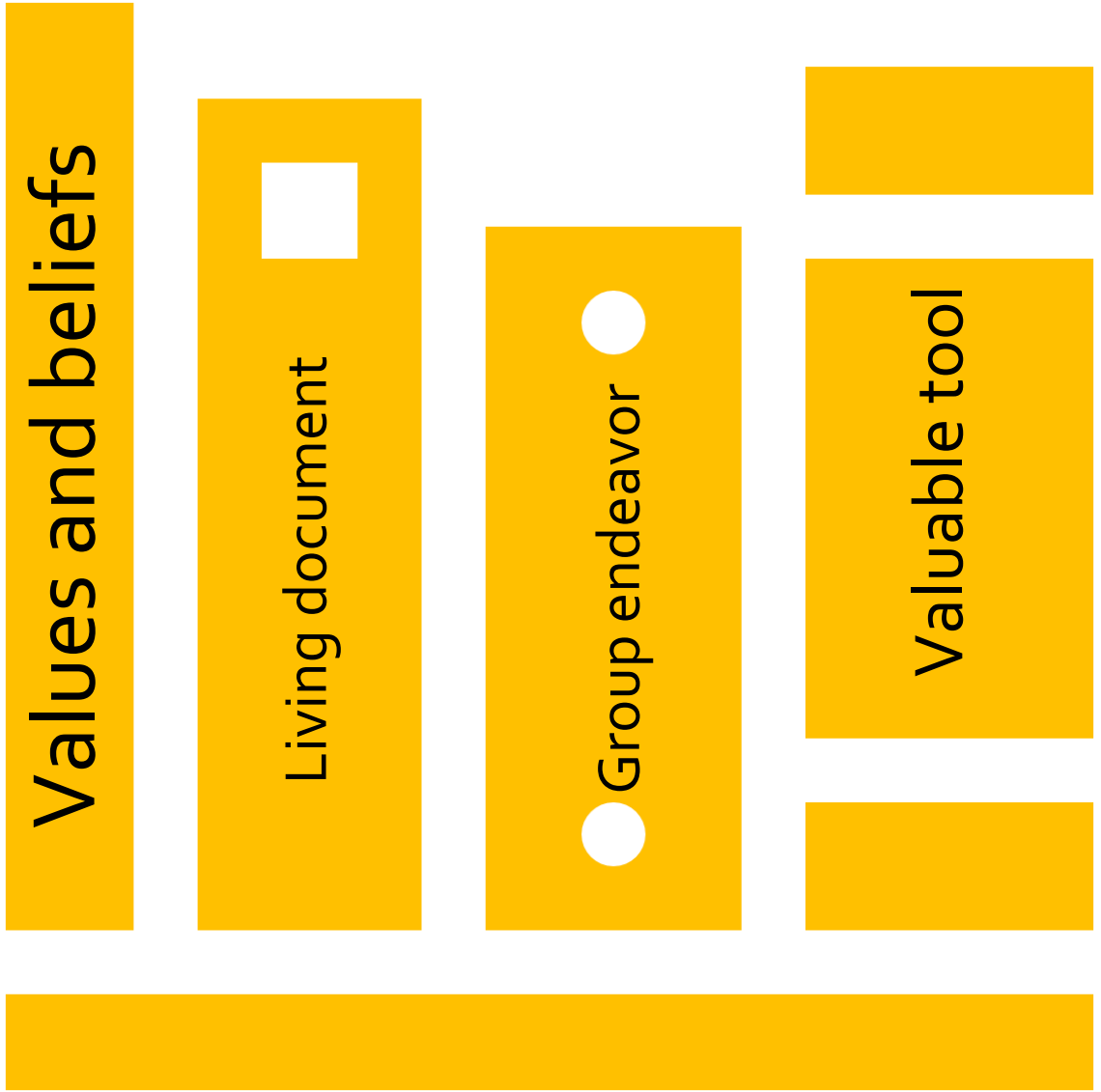
Community Issues

'Family inclusive' care?

More than partners in care

Meeting their needs

Philosophy



Assessments

What are the needs and preferences of:



Unless there is follow-through, your time has been wasted.

Paths of Communication



 Center

 Family

 Family

 Family

 Center

 Family



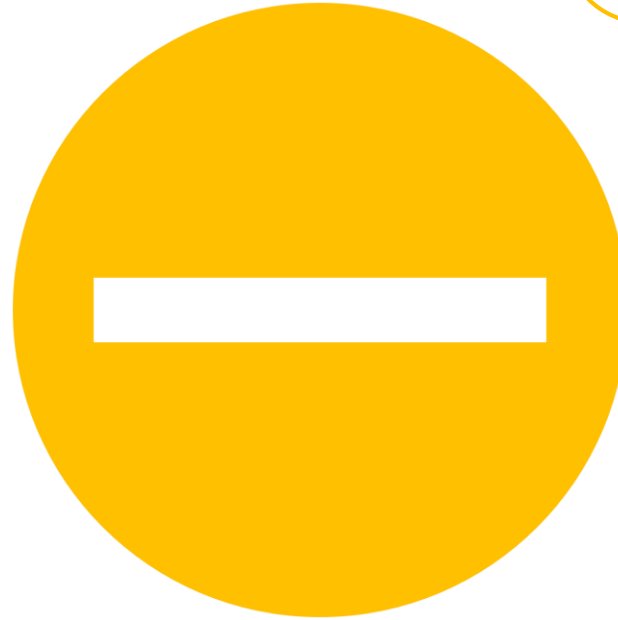
Effective Communication

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



How good are your skills?

Barriers to Communication



Perception/interpretation

Generalizations/biases/prejudices

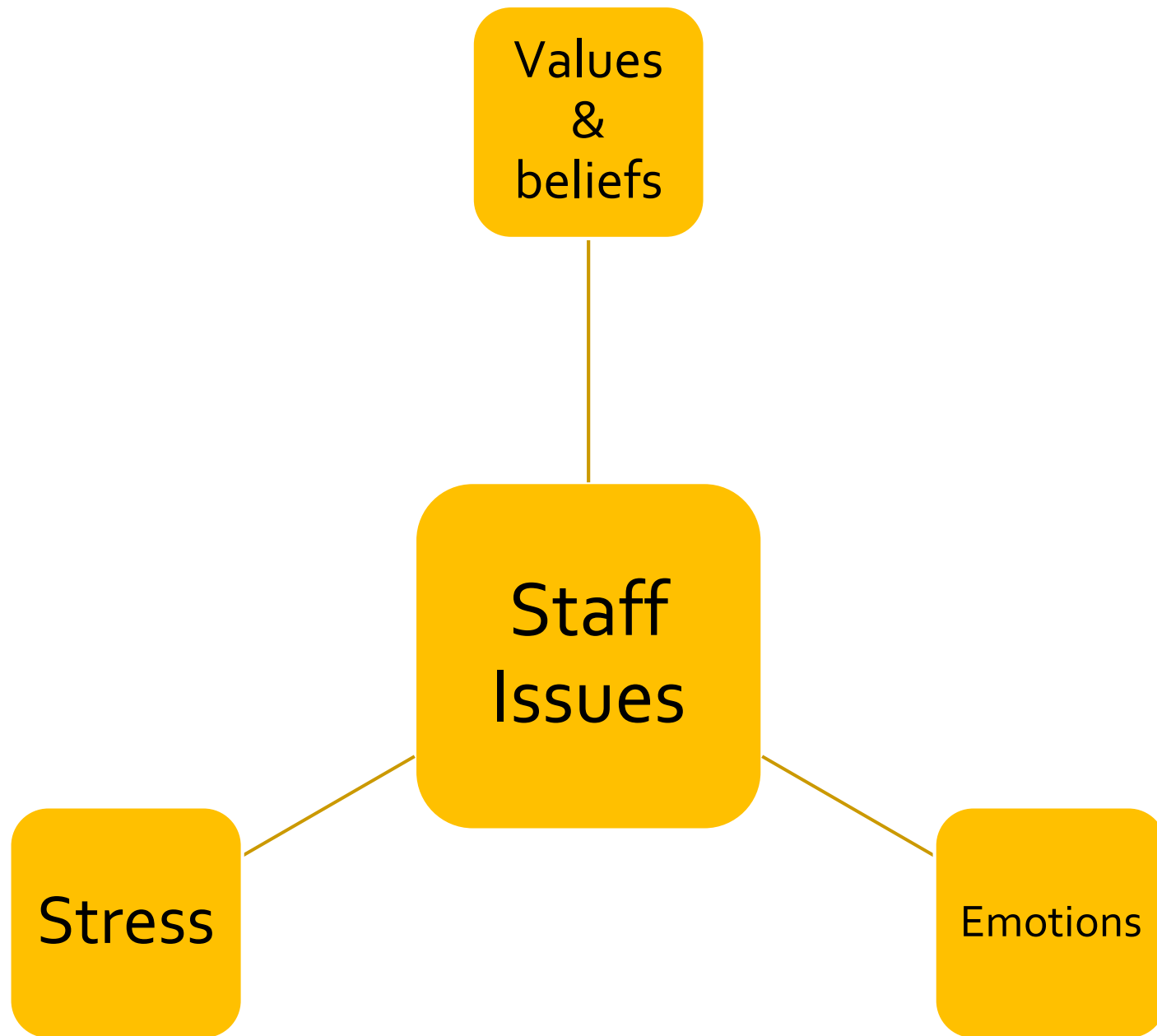
Jumping to conclusions

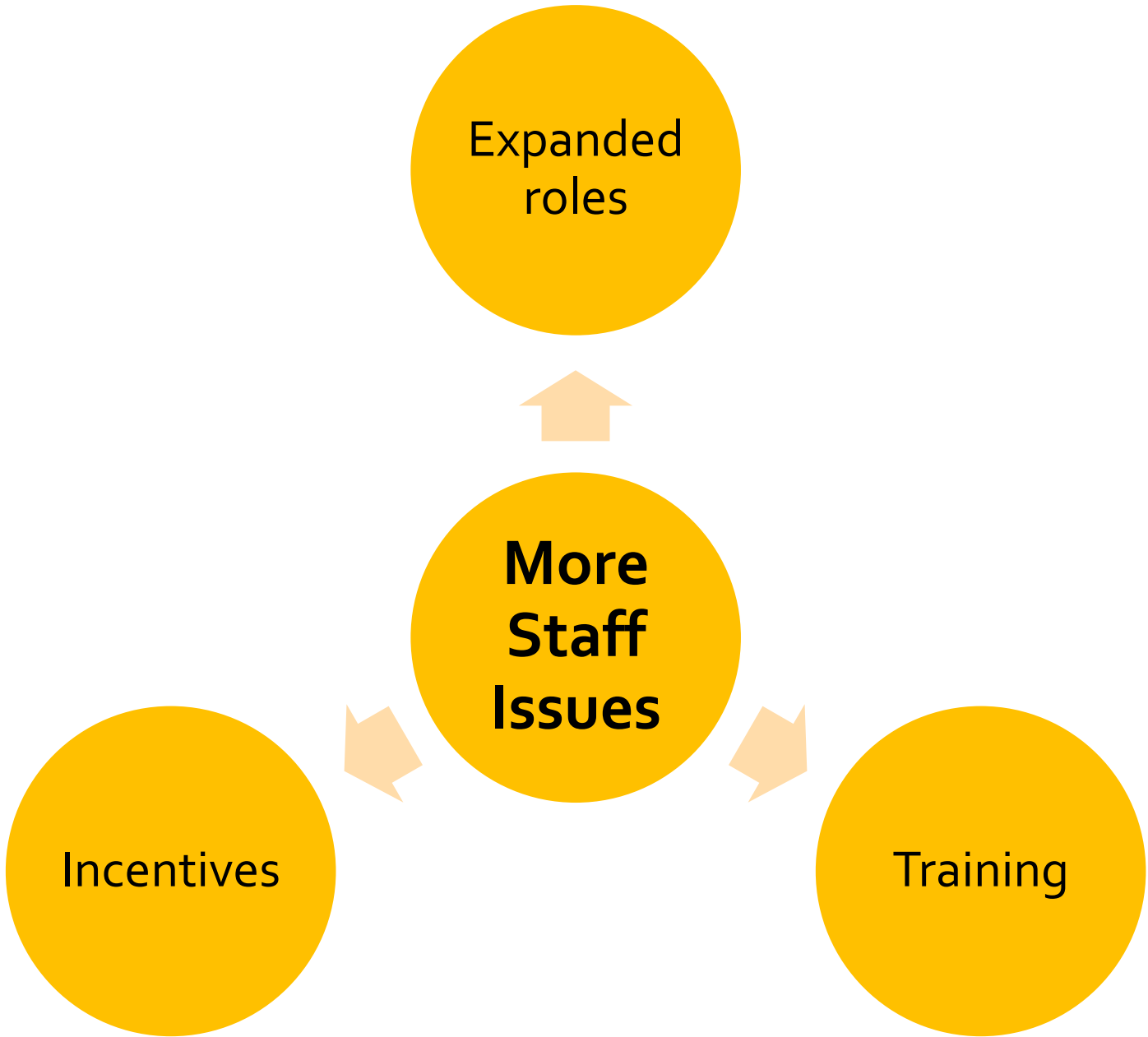
Assumptions

Multiple meanings

Dilution

Message sent, but not received







Conflict

is Inevitable

Disagreement vs. conflict

Expectations & promises

Being heard

The costs of conflict

Negative aftermath

Collaboration not victory

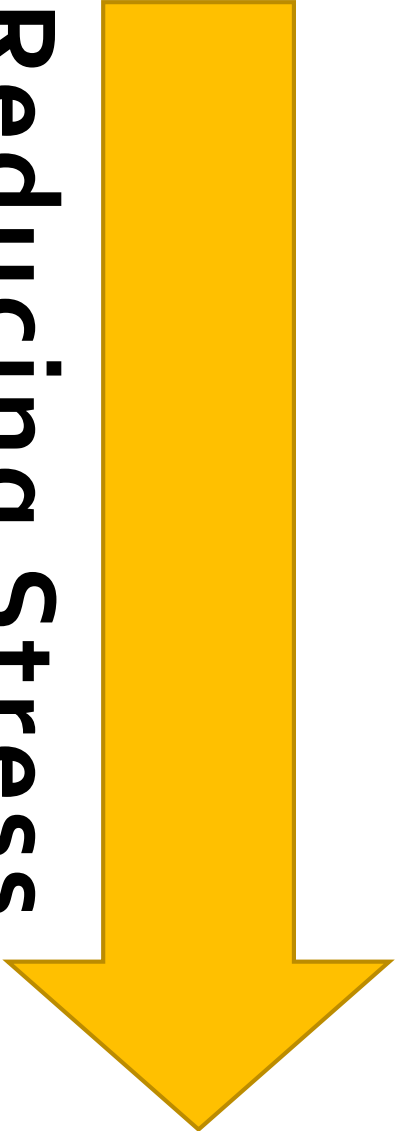
Dealing with Conflict

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

Define the issue objectively.
Monitor your messages.
Go slow. Think.
Respect personal space.
Don't rise to hostility.

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:



- 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

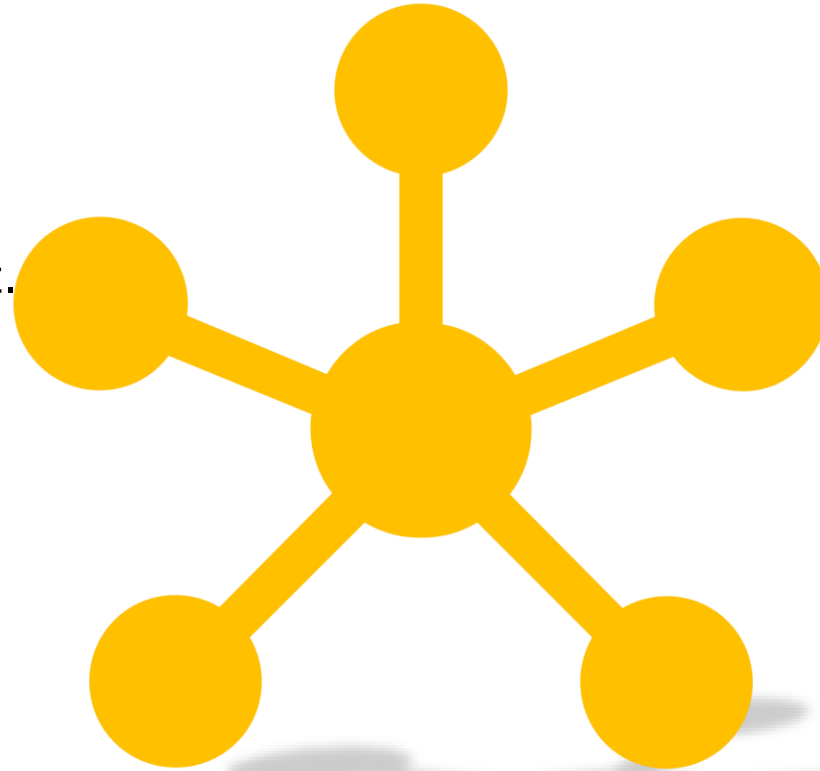
Appropriate way to respond would include active listening and validation of feelings rather than trying to make the person **feel better.**

Network of Support

The message is:

Ask for help. You deserve it.

You are not alone.

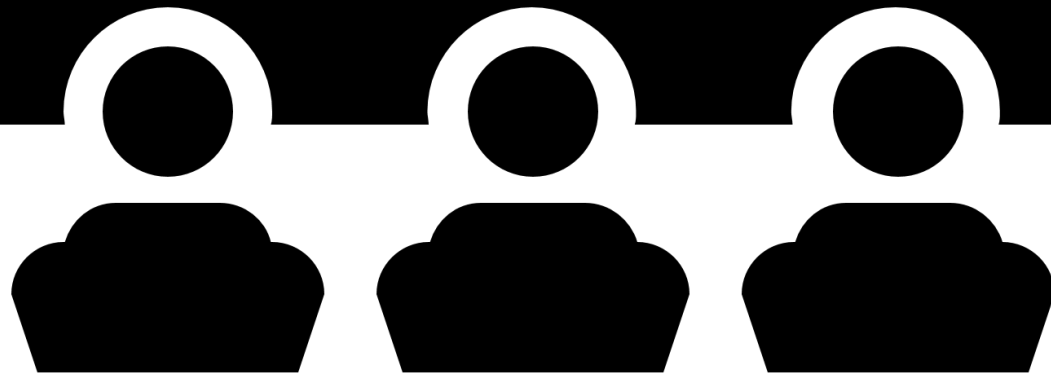


Education is available. It gives you power.

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

Communication and interaction

Meaningful and appropriate activities

Making the most of your visits

How to react to behavior changes

Helping with everyday tasks

What to expect during the course of a disease

Decision-making: financial, and end-of-life

How to cope with a hospitalization

The center's philosophy of care

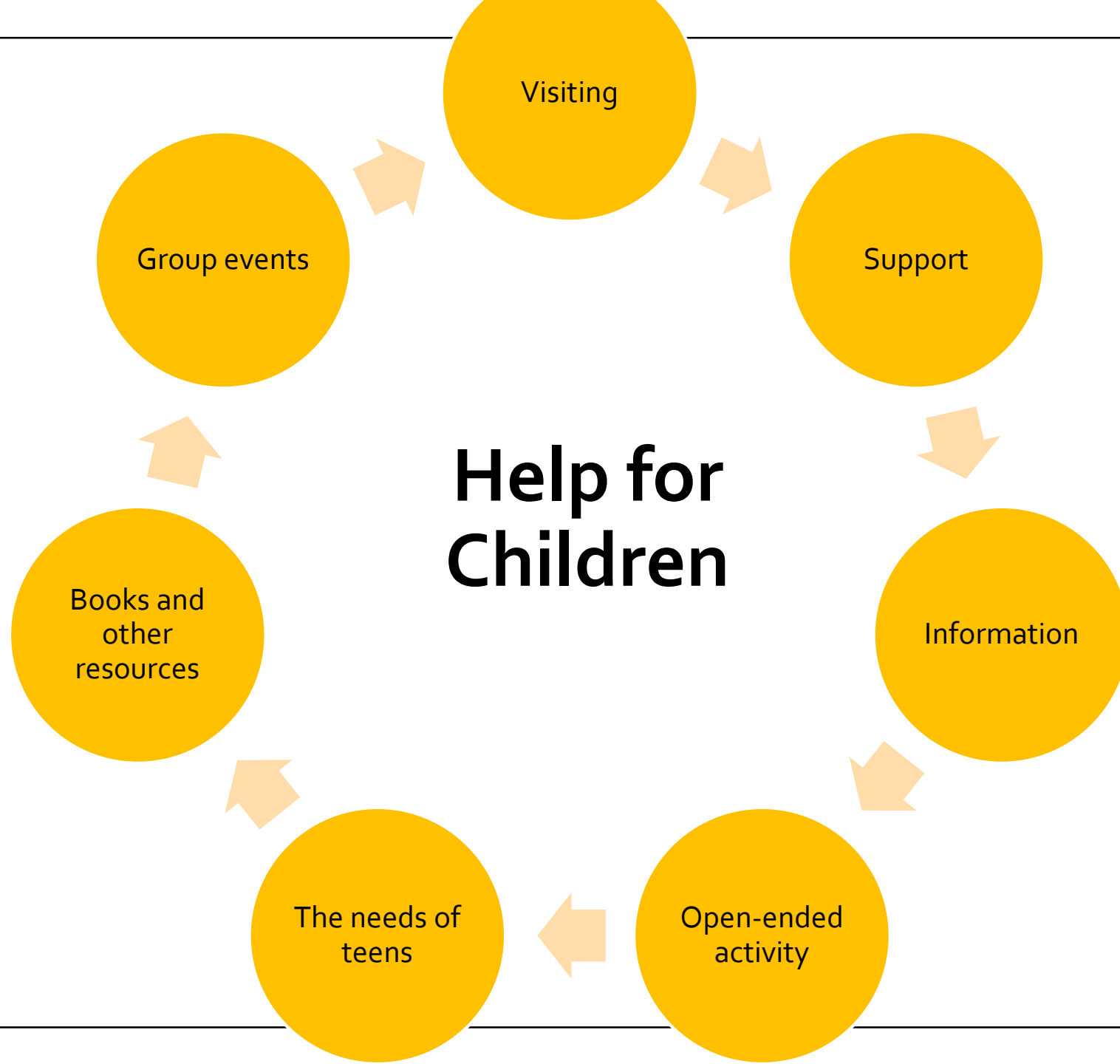
The Young Family Member

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



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

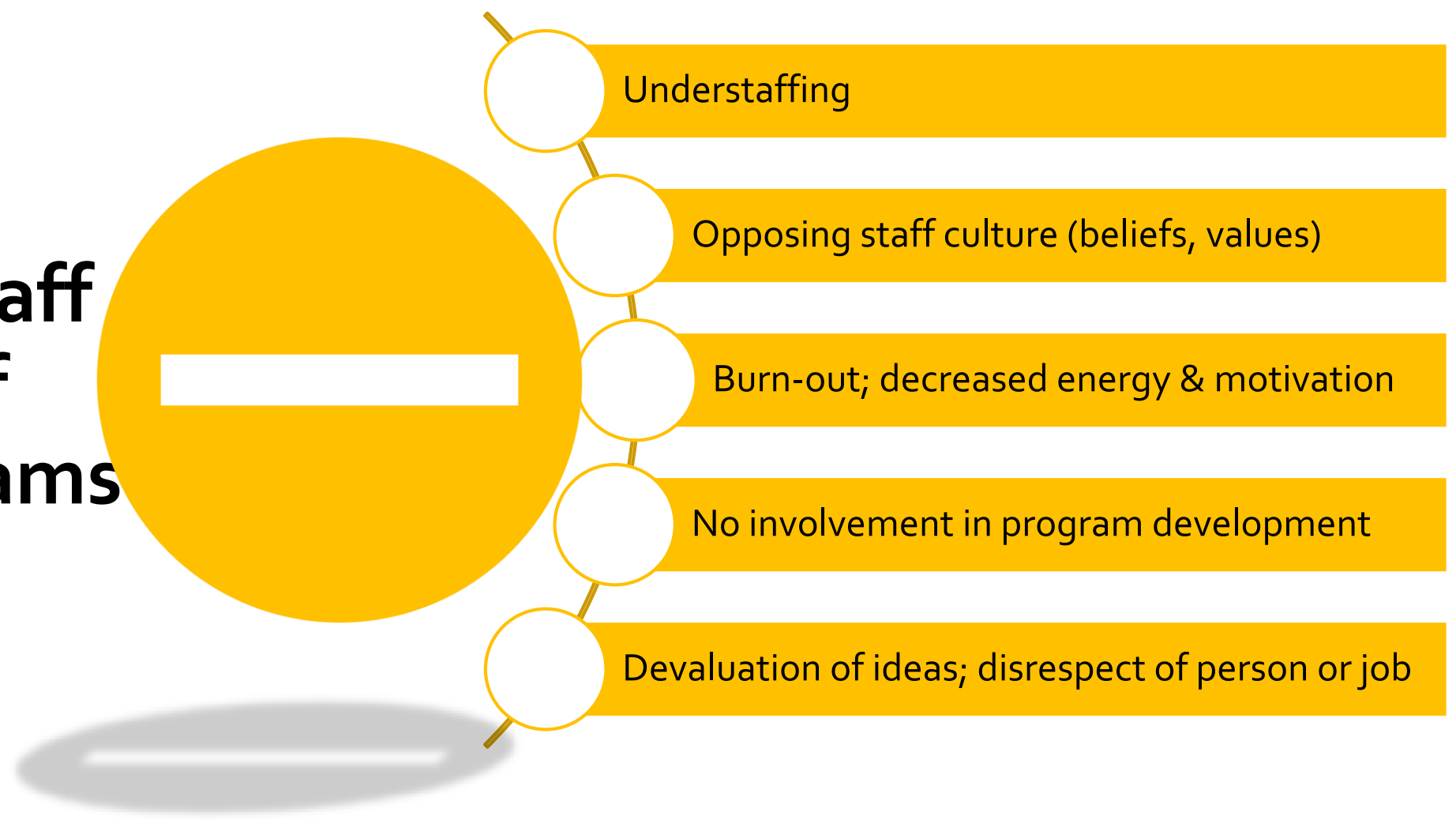
Communication between family and center

Evaluation

Structured Family Programs

- Size doesn't matter!
- Goals
- Framework
- Consistency
- Role definition
- Advertising

Barriers to staff promotion of family programs



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!



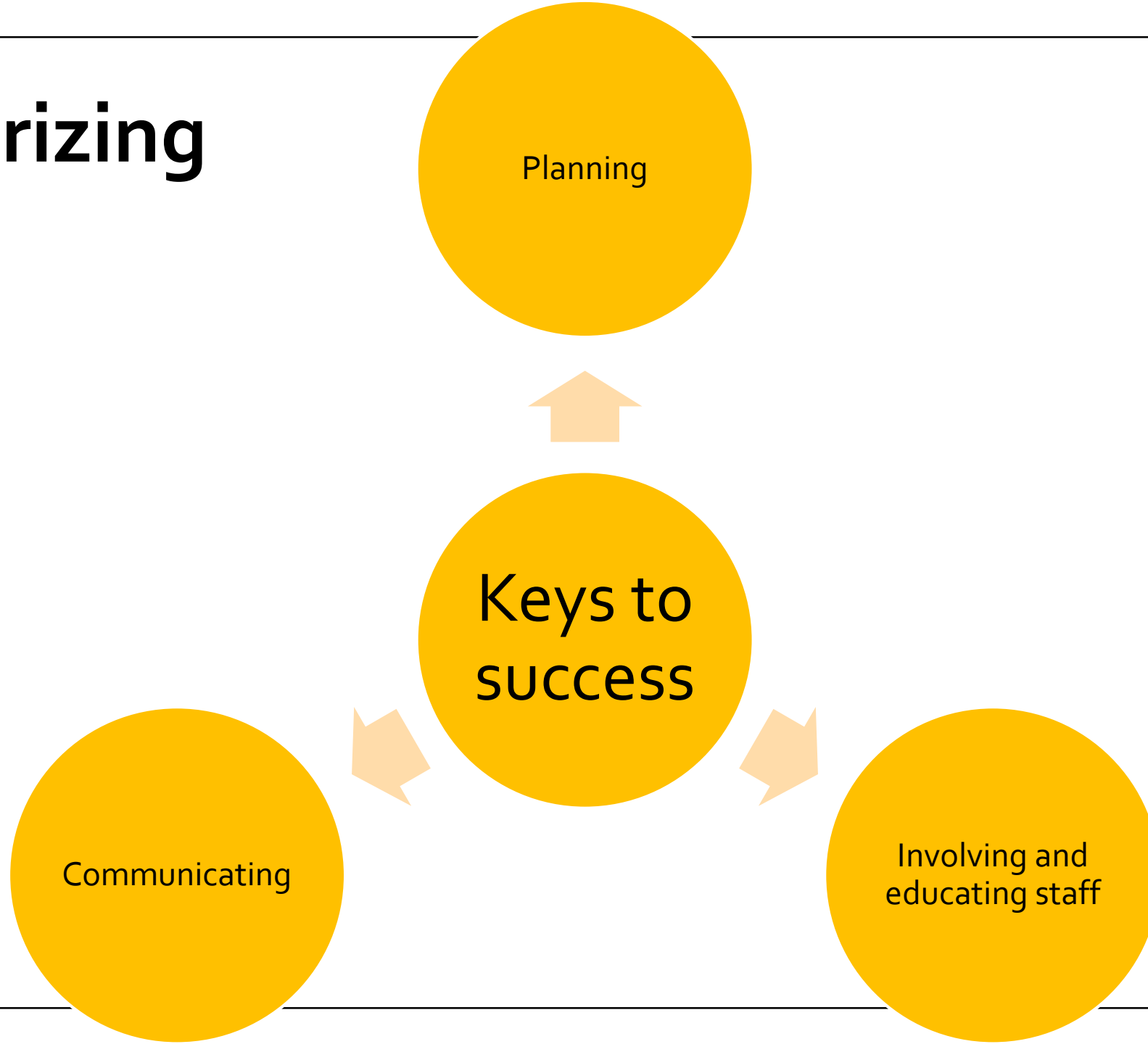
There is no one 'right way' for families to respond to opportunities to participate.

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



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!

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