

Transforming Care Management

An Evidence-based approach for
supporting Family Caregivers

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Goals for Morning

1. Overview of the larger UWM project and its current partners
2. Overview of Caregiver Identity Change Theory as the basis for evidence-based practice.
3. Implications for Service Delivery
4. Introduction to the **U**niform **C**aregiver **A**ssessment and **RE**ferral (**UCARE**) *process*.
5. Future directions and opportunities for Washington Partners.

Part I: Overview of Research and Development Activities

Research Team

Rhonda J.V. Montgomery (UWM)

Karl Kosloski (UNO)

Mary Brintnall-Peterson (UW-Extension)

Vicki Schmall, (Aging Concerns – Oregon)

Jeannine Rowe (UWM)

**Dale Adler (Gerontology Programs
Consultant)**

& Team of hard-working graduate students

Practice Partners

State and local agencies in

- Florida
- Georgia
- Michigan
- Washington
- Wisconsin

Transforming Care management

- Family Caregiver Assessment Tool
- Evidenced-based Care Management protocol
- Coordinated training curriculums for
 - Family caregivers &
 - Care managers / Family Specialists

WHY?

- Family Caregivers are
 - Key partners in long term care
 - Key to quality elder care
- Programs that are looking for guidance:
 - National Family Caregiver Support Program (AoA)
 - Aging Network Services
 - ADRC (SPE)
 - Medicaid waiver programs
 - Chapter Network of Alzheimer's Association

Our Vision

- **Care managers and family caregivers will determine needs through**
 - **an assessment process**
 - and**
 - **match appropriate community services to meet the identified needs.**

How?

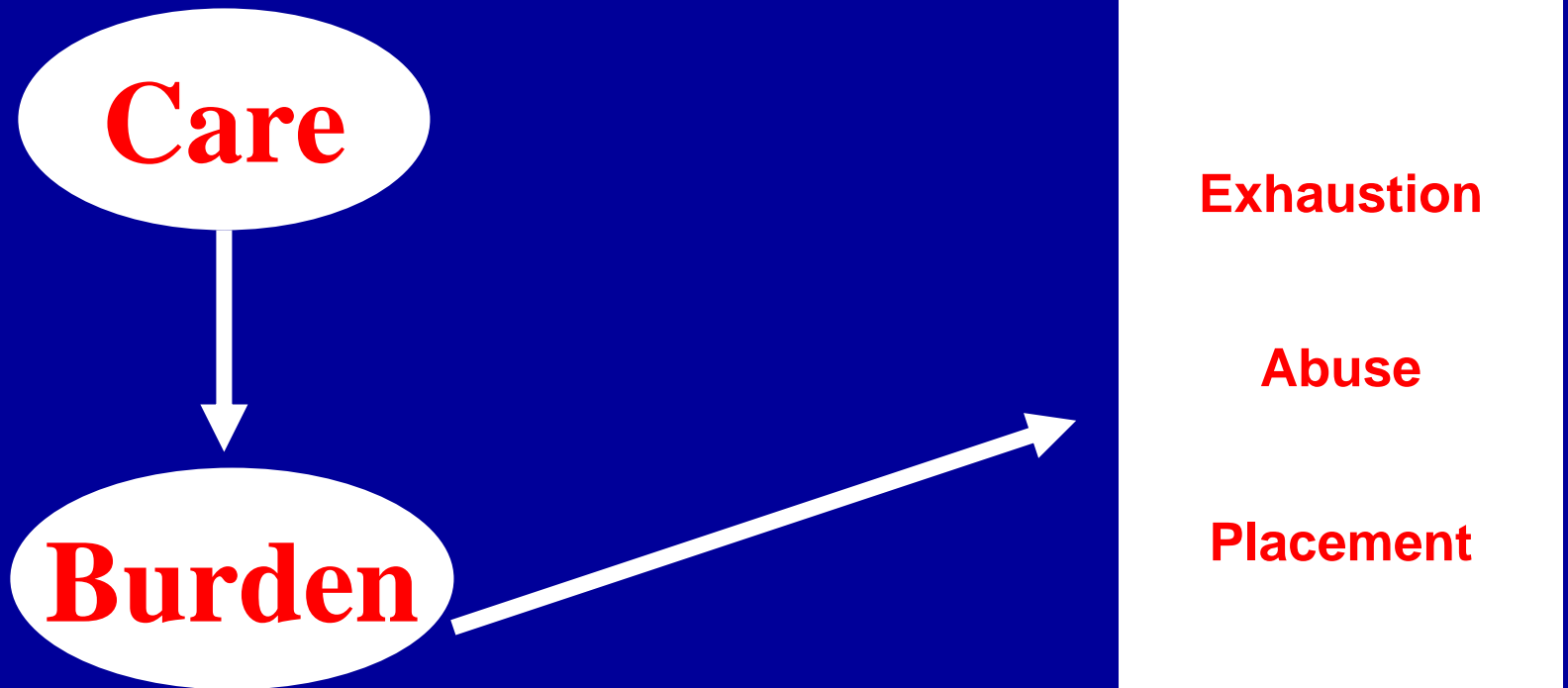
Target services effectively

- Identify caregivers' needs
- Understand goals for intervention
- Match services with goals
- At the correct time
(when caregivers can & will use service)
- Increase compliance

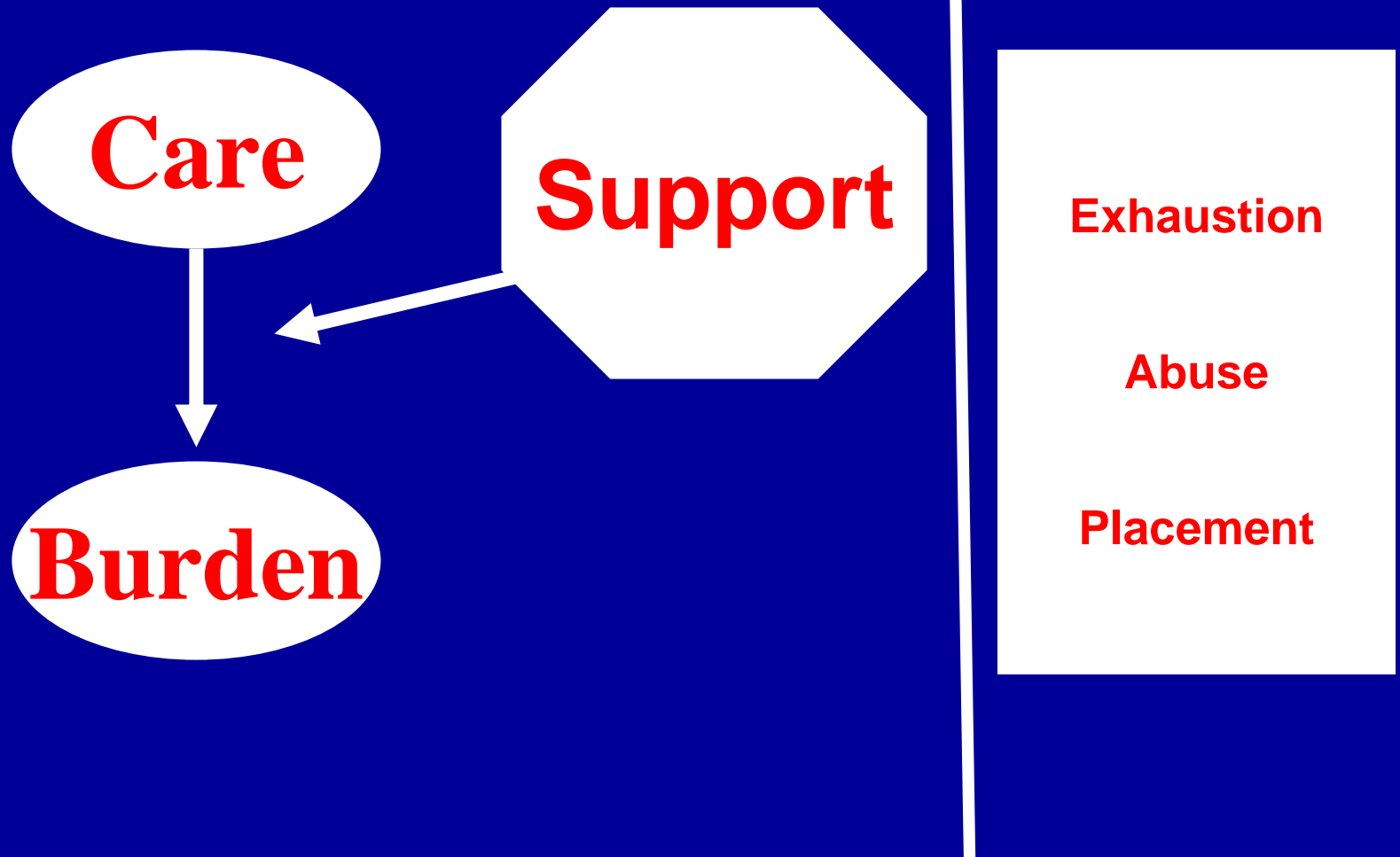
Analogy to medicine

- Right diagnosis (identify the needs)
- Goal- Cure or symptom?
- The right medicine
(correct service)
 - The right dosage
(sufficient quantity)
- At the right time
(prevention not cure)
- Increase Compliance (take the medicine)

Common Stress Model as Rationale for Support



Rationale for Support



Goal of our Work

- Maximize impact of support services for family caregivers
 - Serve More Clients
 - Provide better support
- Minimize costs

Must assess the client “family”

- The client is the family
 - Caregiver
 - Care recipient
 - Family Care context
- Current practice:
 - Look at care recipient as only client
 - View family as “visitor or servant”

Care Receivers' Needs Don't Predict Intention to Place

Measures of Need	Intention to Place
ADL/IADL	.14
Problem behaviors	-.07

Caregiving Activities Don't Predict Intention To Place

Hours in past week spent doing :	Intention to Place
Personal Care	-.11
Housework	-.16
Transportation	.01
Banking/Legal Matters	-.02

Need for Guiding Model

- Understand Source of Distress
- Helps identify characteristics that are appropriate to measure
- Points to strategies for intervention



Diversity Among Caregivers Affects Journey

- Relationship
- Gender
- Culture
- Caregiving Environment
 - Functional level of care recipient
 - Living arrangement
 - Formal Supports
 - Informal Supports

Diversity in Experience

- Comfort level with role
- Relationship between CG & CR
- Overload or interference with life
- Anxiety or stress
- Depression
- Positive feelings

Pathways Through Caregiving: the Caregiver Identity Model

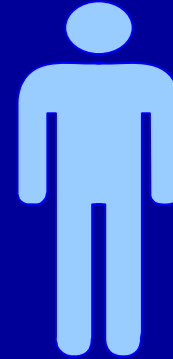
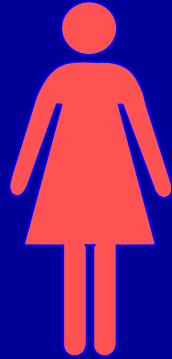
1. Caregiving involves an **identity change process** .
2. Change often involves a lag time when there is a misfit between what a caregiver is doing and what the caregiver thinks she/he should be doing. **Lag causes stress.**
3. To fully support families we must use strategies to identify this **source of stress** and **remove the “discrepancy”** with appropriate interventions .

Basic Premises About Caregiving Journey

1. There is no single, generic caregiver role

- Caregiving role emerges from -
prior role relationships
- Role influenced by the –
unique values, beliefs and circumstances

Spouse/Partner



Emotional

Banking

Errands / Shop

House Tasks

Decision Making

Emotional

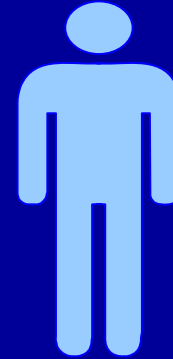
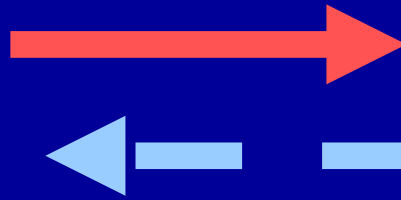
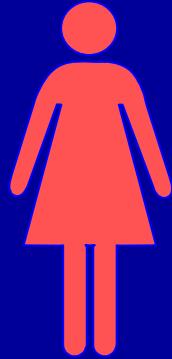
Banking

Errands / Shop

House Tasks

Decision Making

Spouse/Partner as Caregiver



Emotional

Banking

Errands / Shop

House Tasks

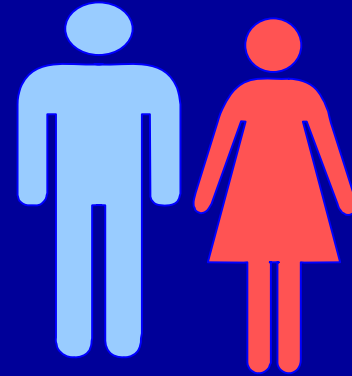
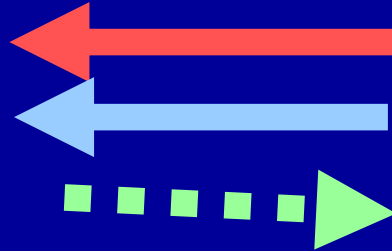
Decision Making

Personal Care

Emotional



Child



Emotional

Emotional

Banking

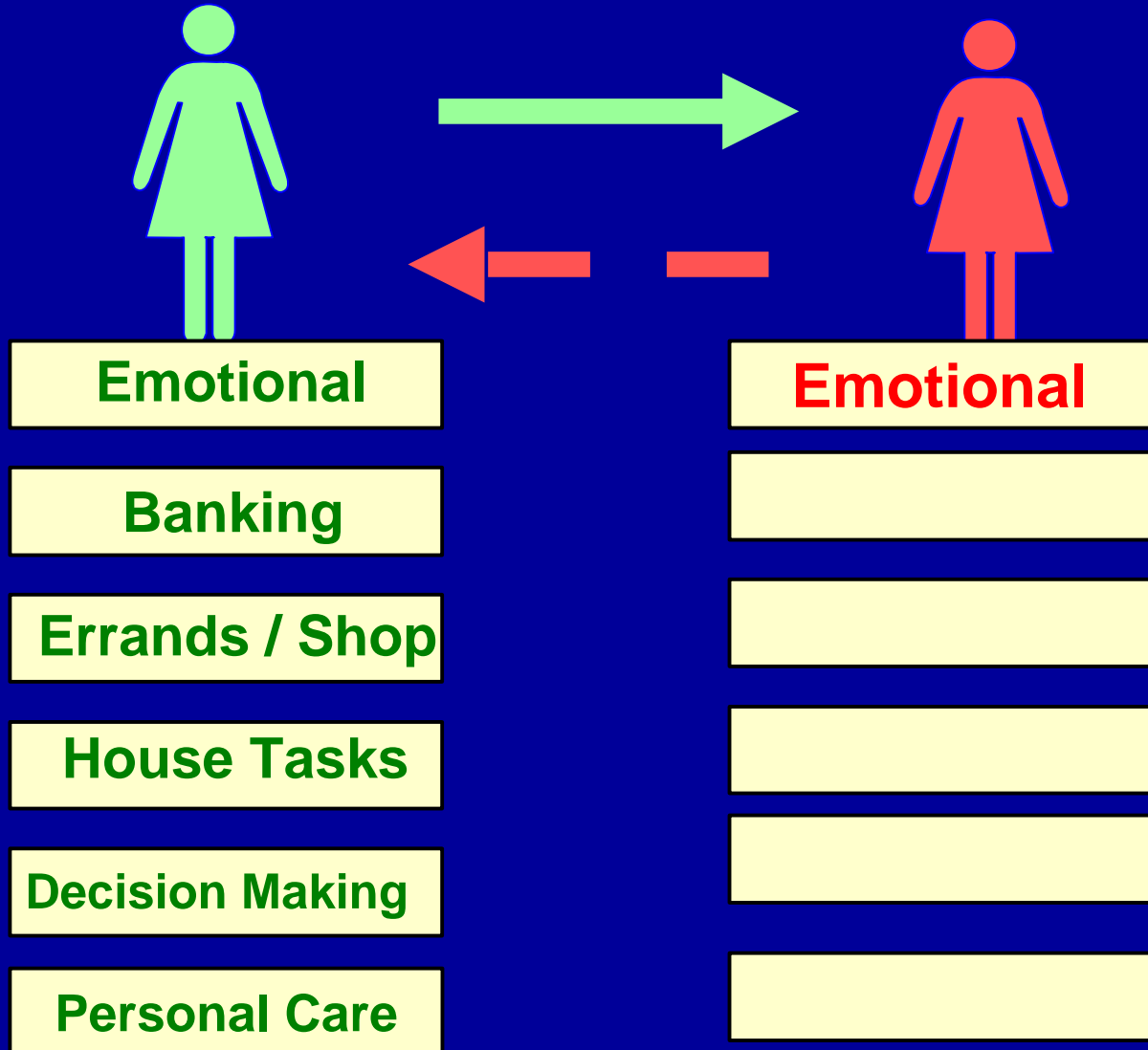
Errands / Shop

House Tasks

Decision Making

Personal Care

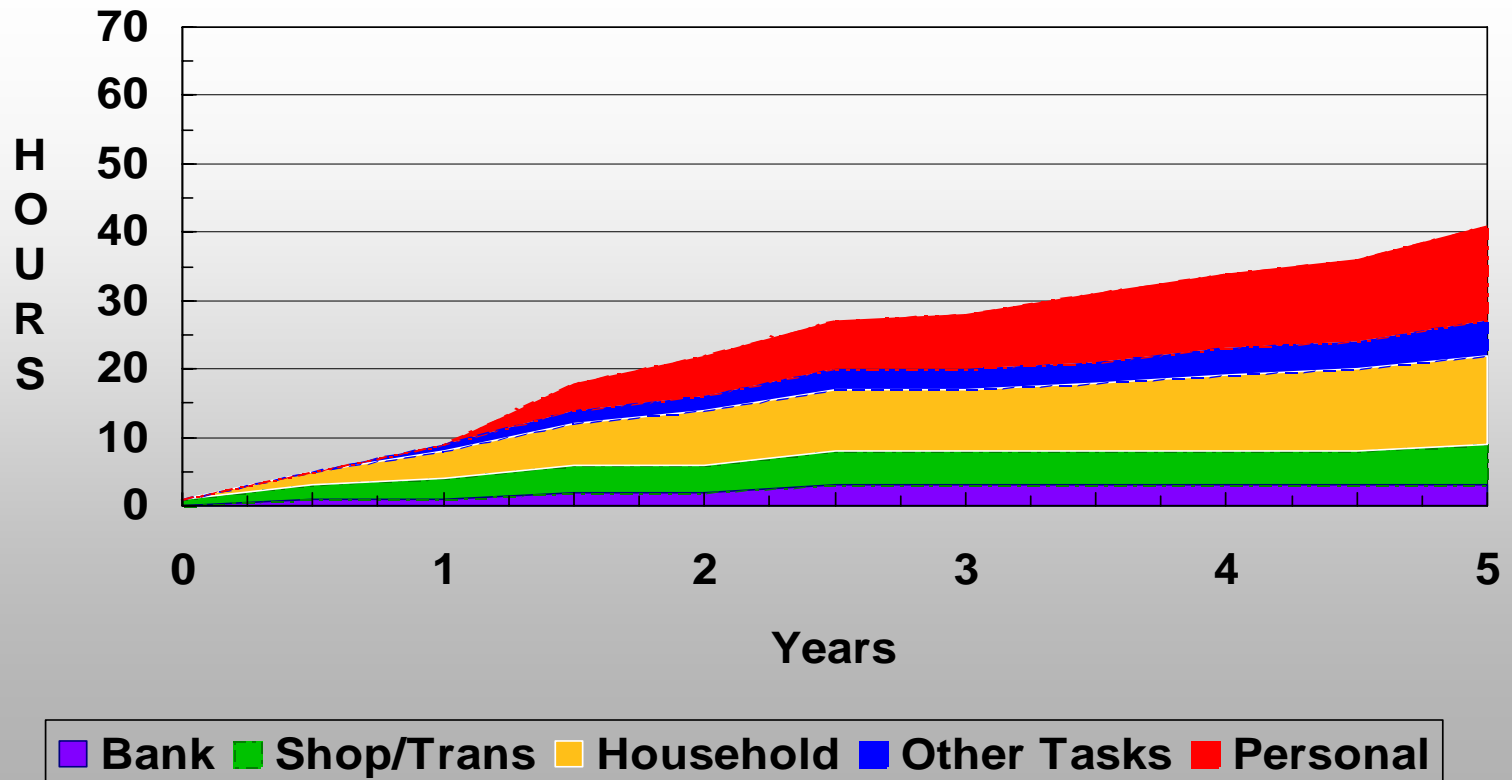
Adult-Child as Caregiver



Basic Premises about Caregiving Journey

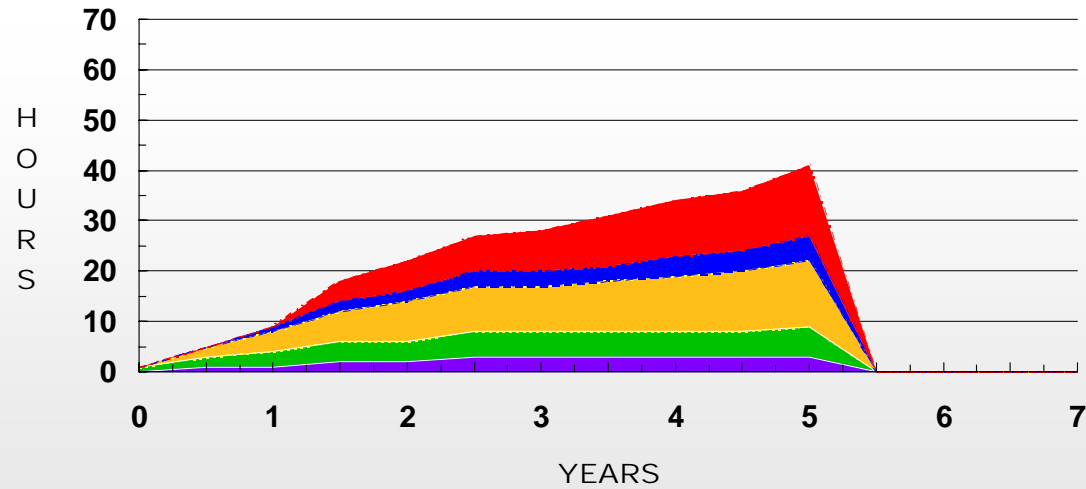
2. Caregiving is a dynamic process that unfolds over time.
3. The length of career varies

Caregiving Journey: Child

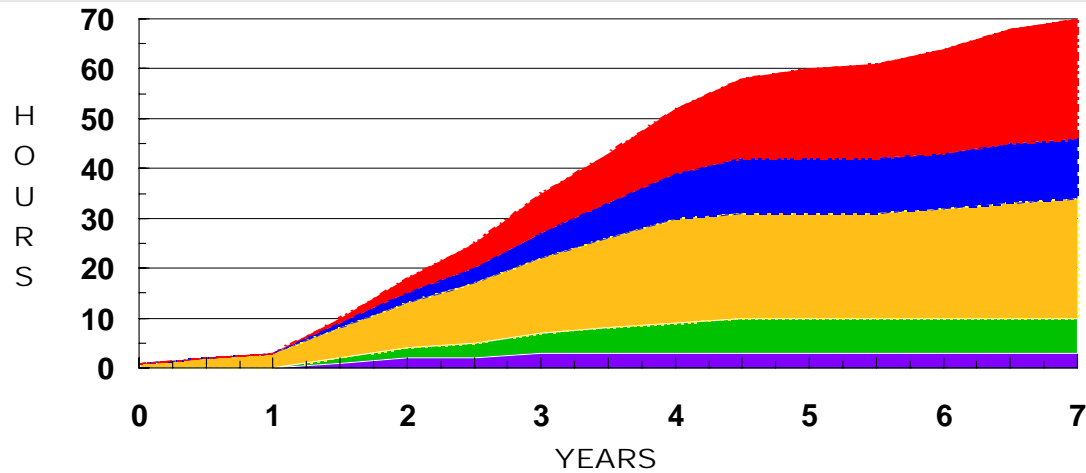


Comparing Journey

CHILD



SPOUSE

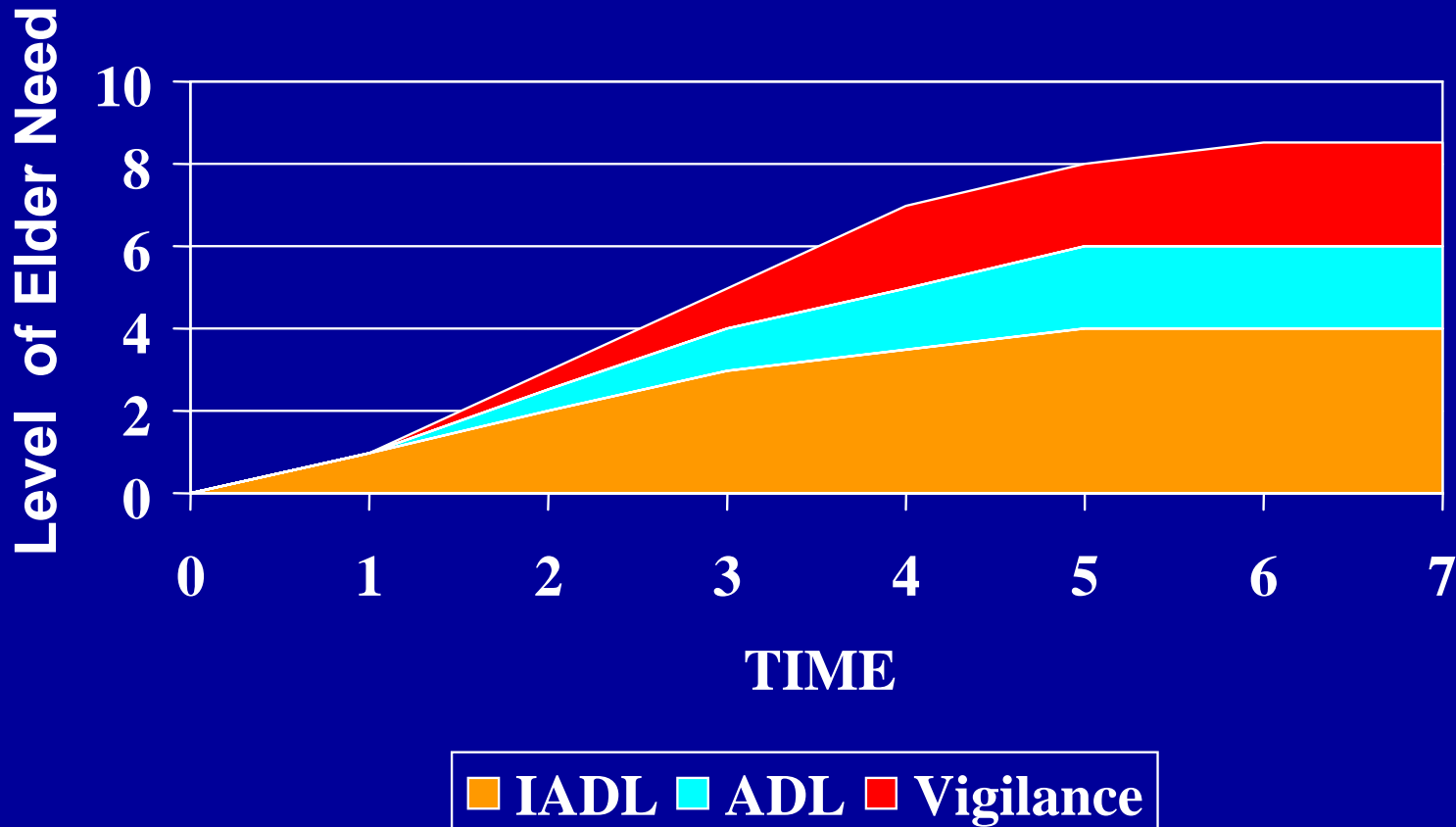


Bank Shop/Trans Household Other Tasks Personal

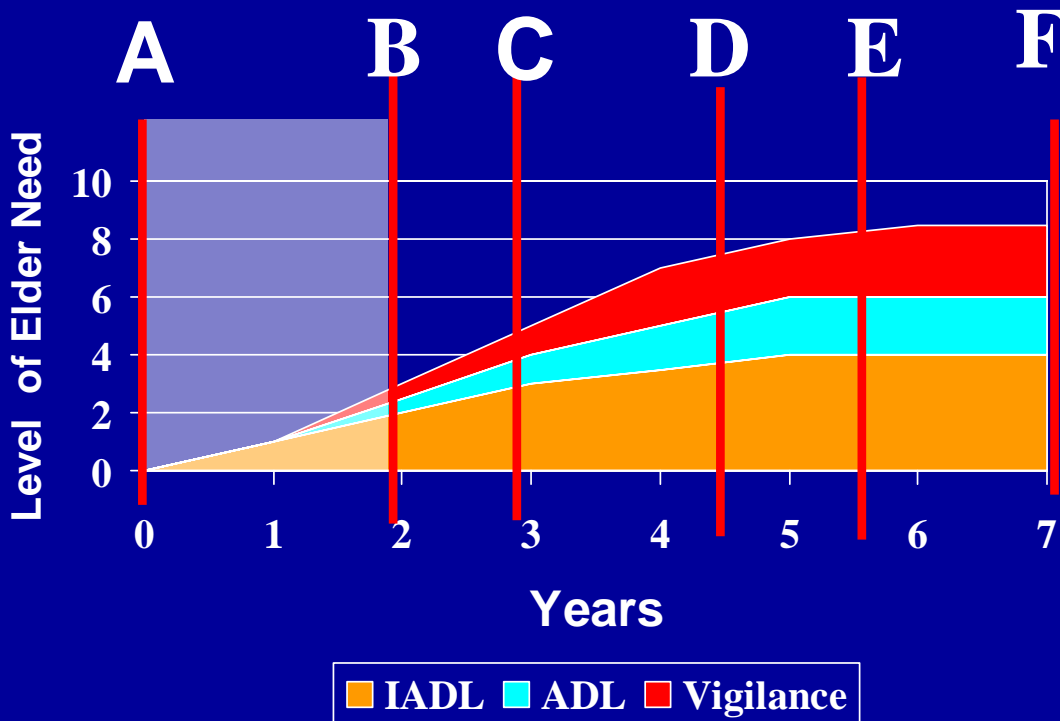
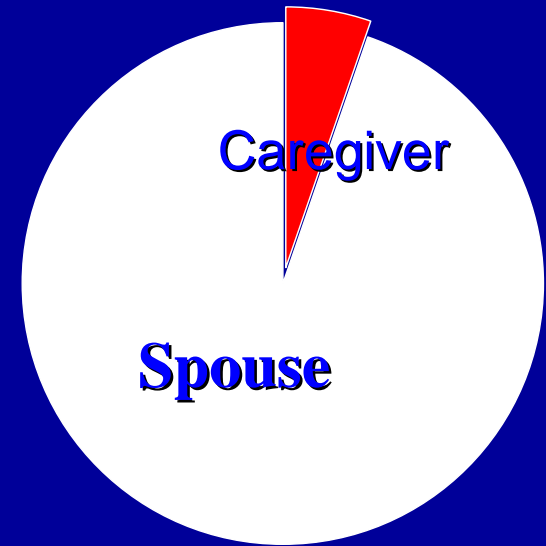
The Caregiving Journey Is a Systematic Change Process

- Change in *activities*
- Change in *relationship* with care receiver
- Change in *role* and *identity* of caregiver

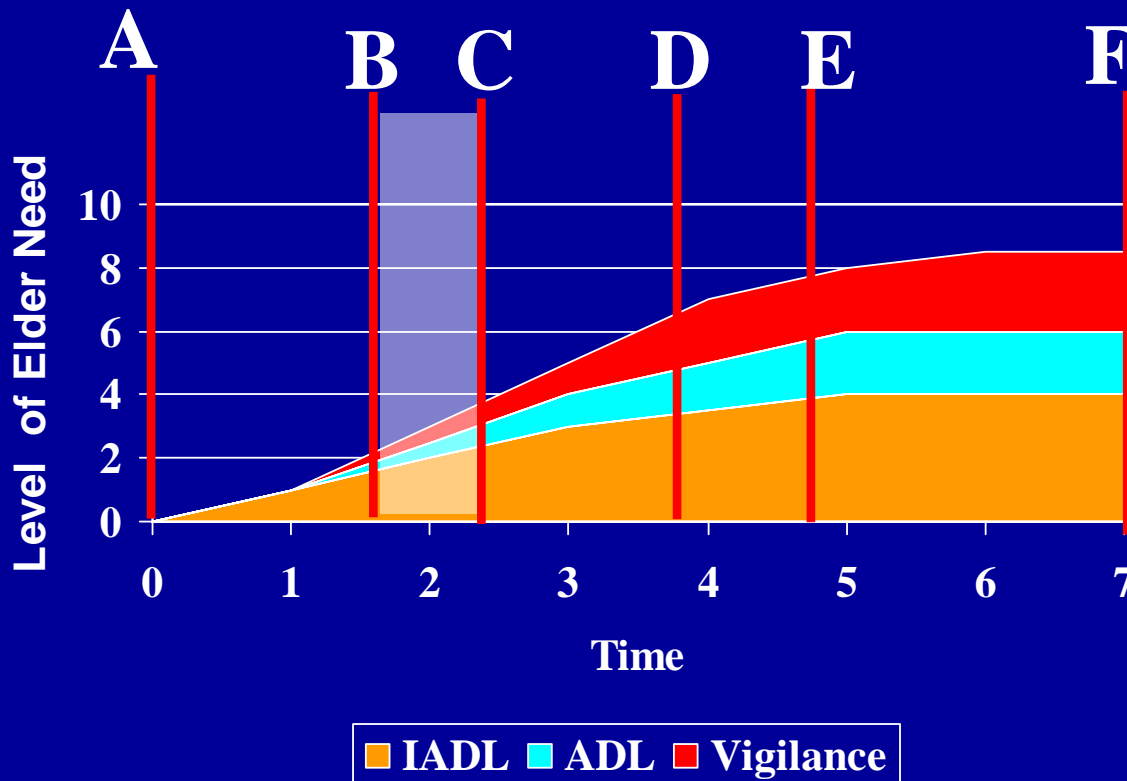
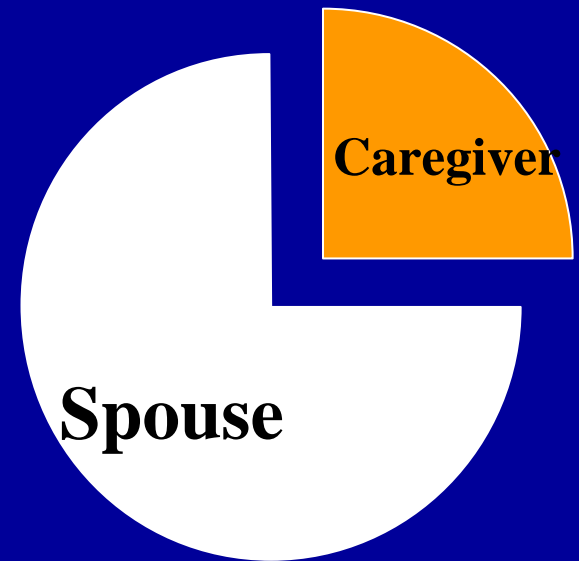
Landscape for Caregiver's Journey



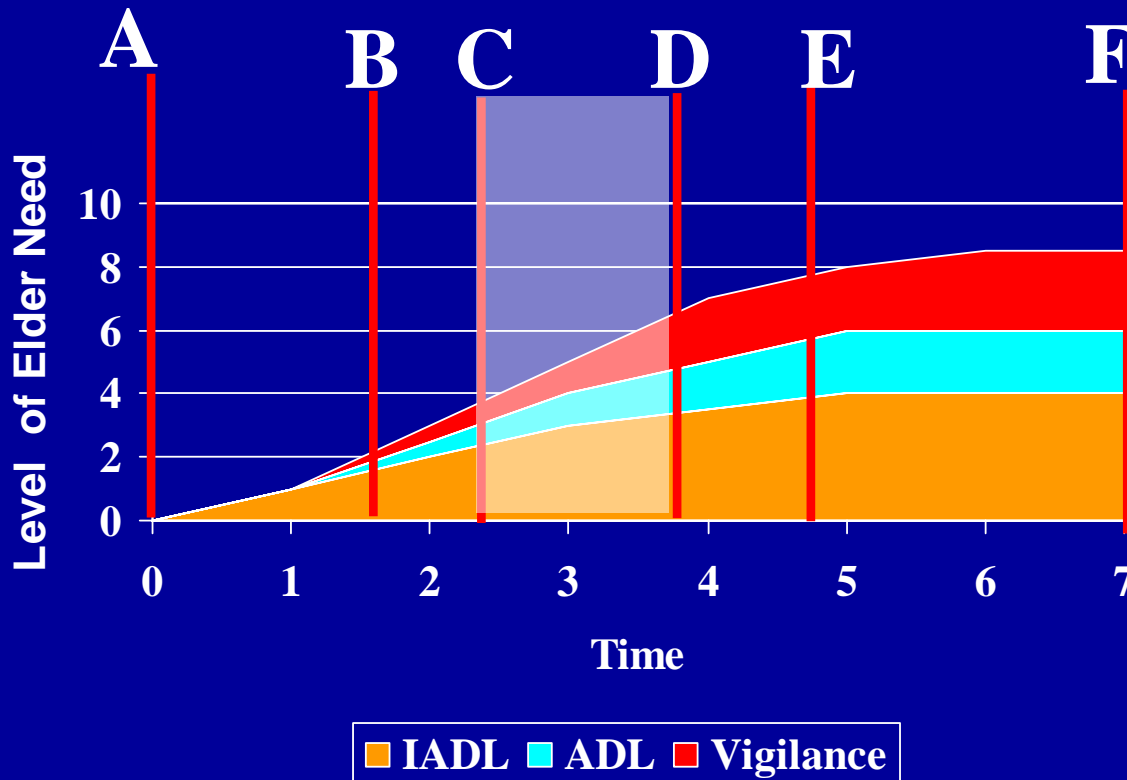
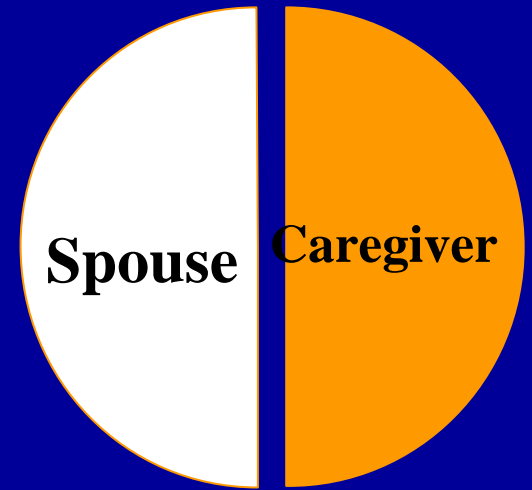
Identity in Phase I



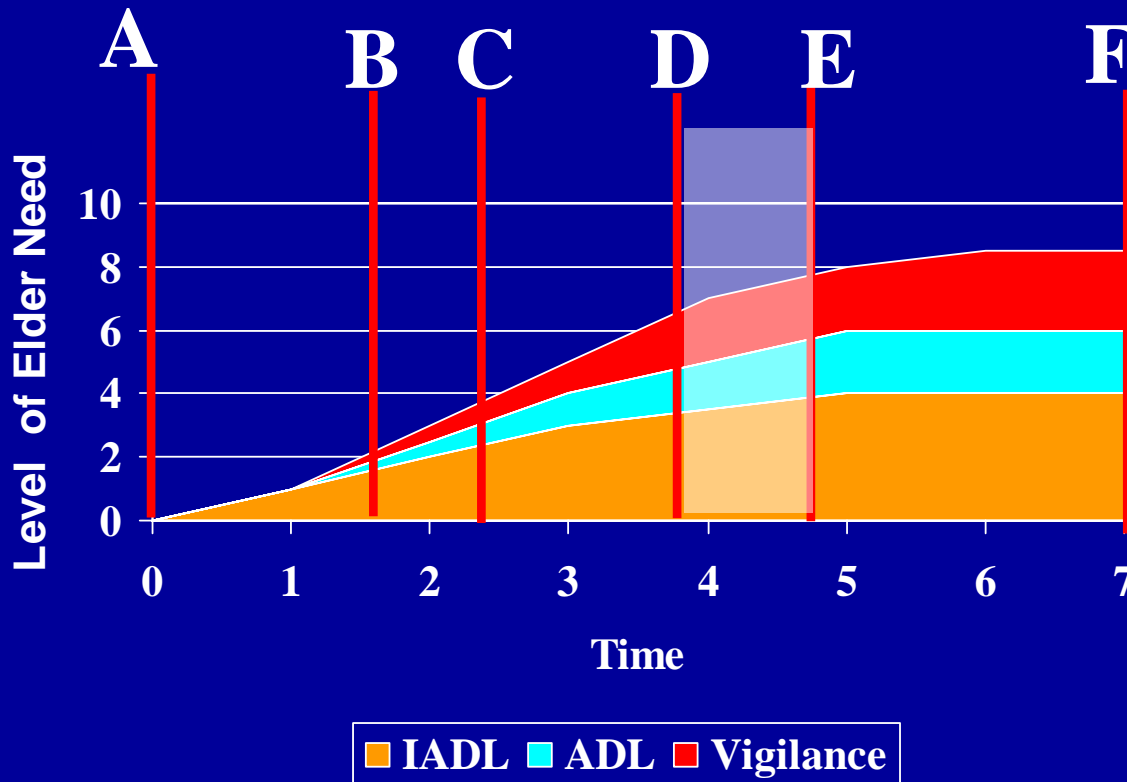
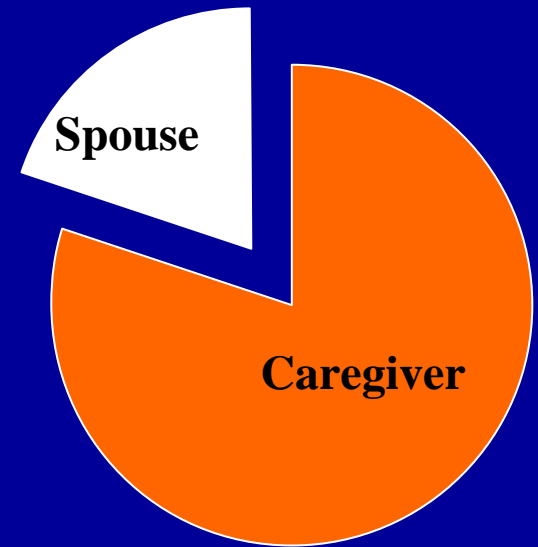
Identity Phase II



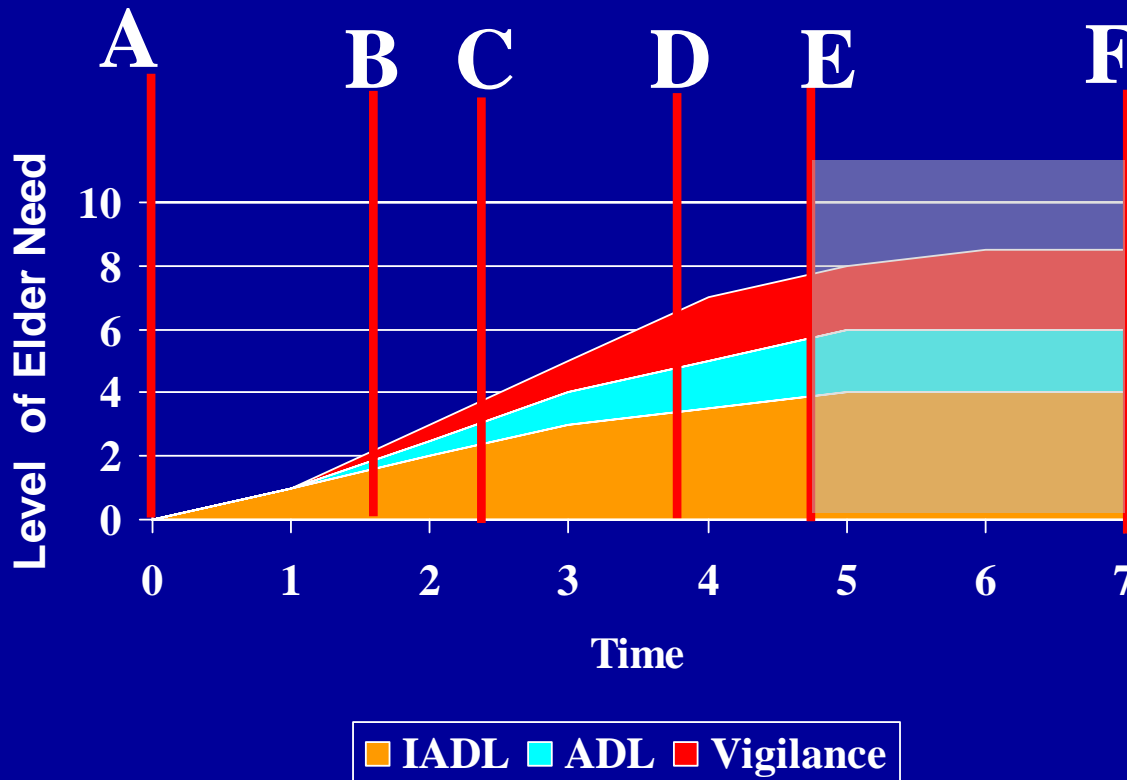
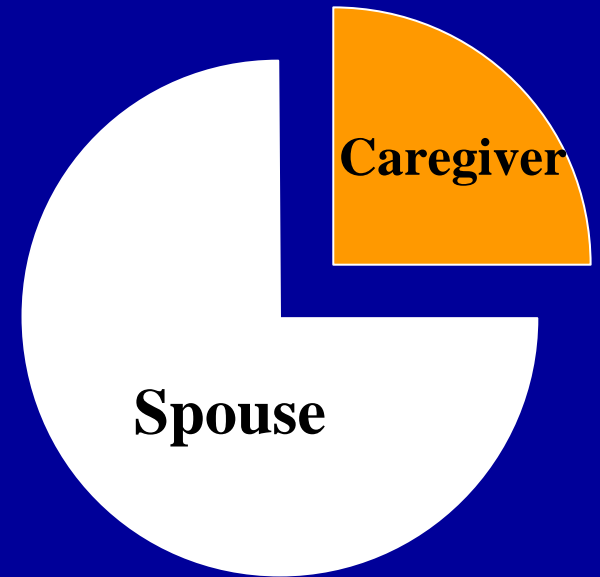
Identity Phase III



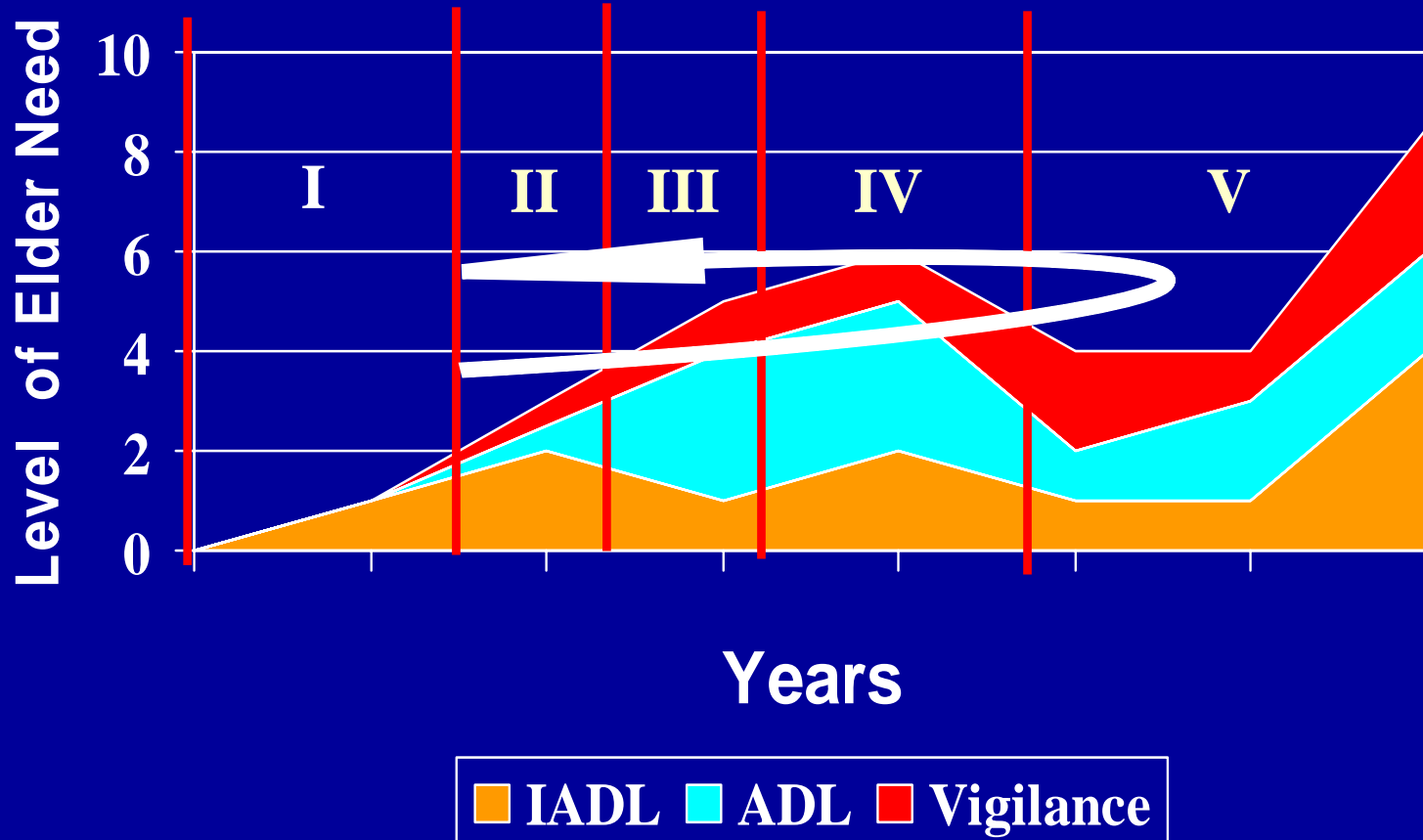
Identity Phase IV



Identity Phase V



Pathways through the Caregiver Journey



Diversity of Relationships affects the “rules for being a caregiver”

- Who becomes caregiver
- How they perform
 - What they do
 - How they do it
- How they feel about it
 - Burdens
 - Uplifts

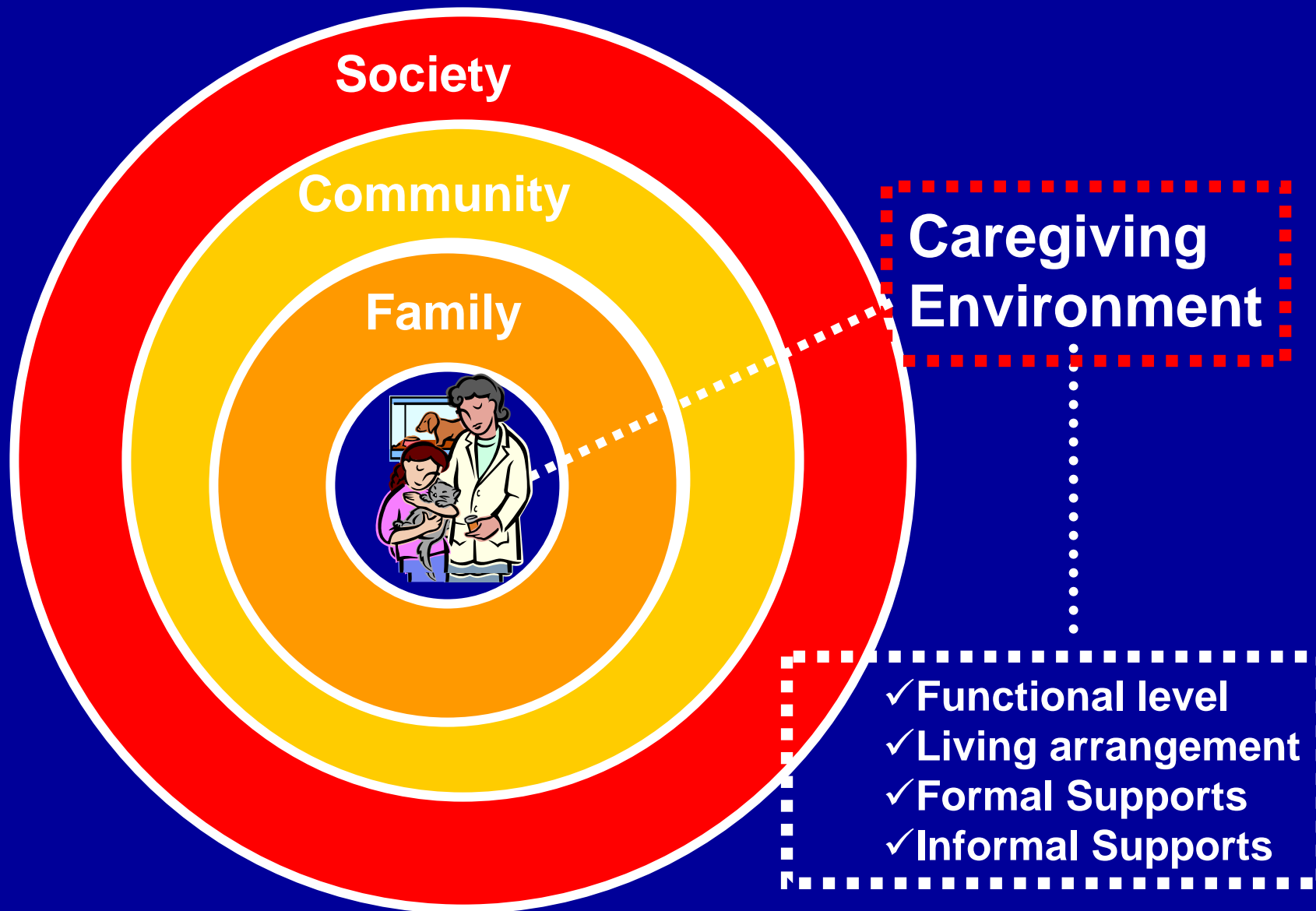
Basic Premise 4: About Caregiving Journey

The general social & cultural rules governing family relationships create *consistencies in the caregiving process.*

- But -

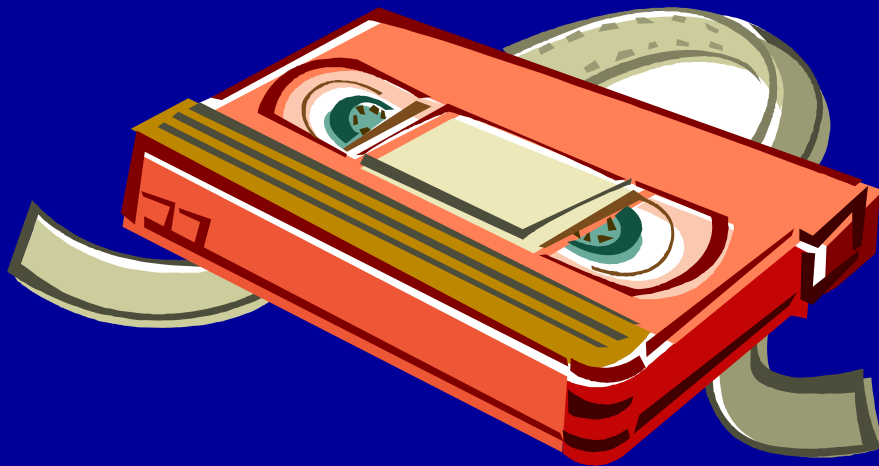
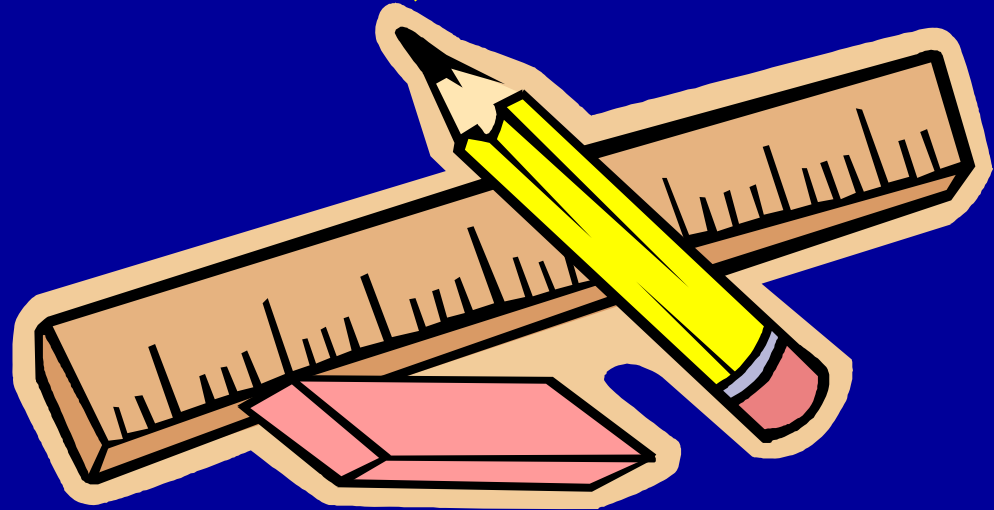
Unique experiences, family histories and cultural adaptations of rules create *unique adaptations* to this *caregiving process.*

Circles of influence



Rules for Behavior (Identity Standards)

We know how to act
because we follow
our internalized rules.

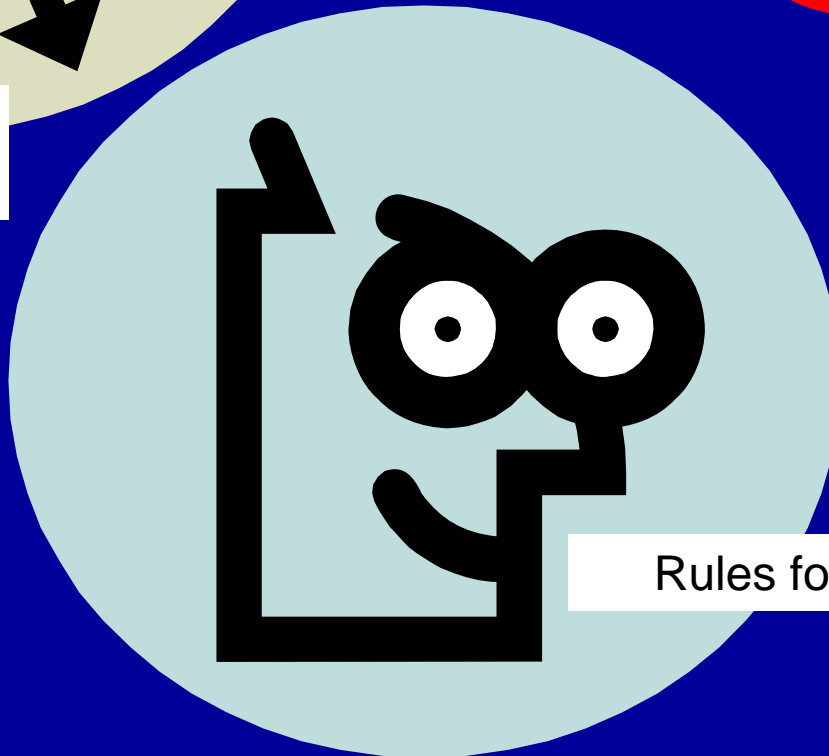




Rules for being a
Wife



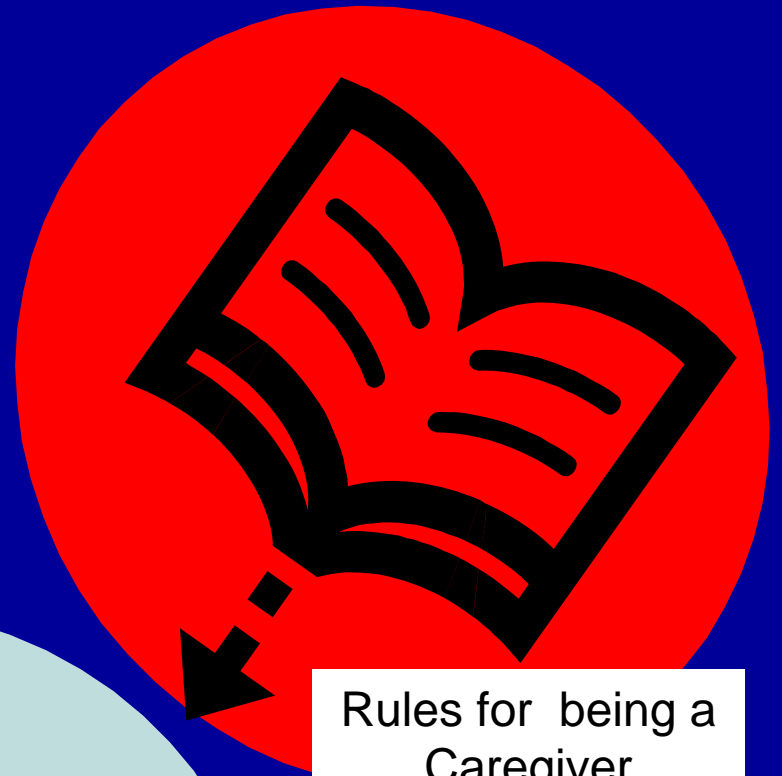
Rules for being a
Caregiver



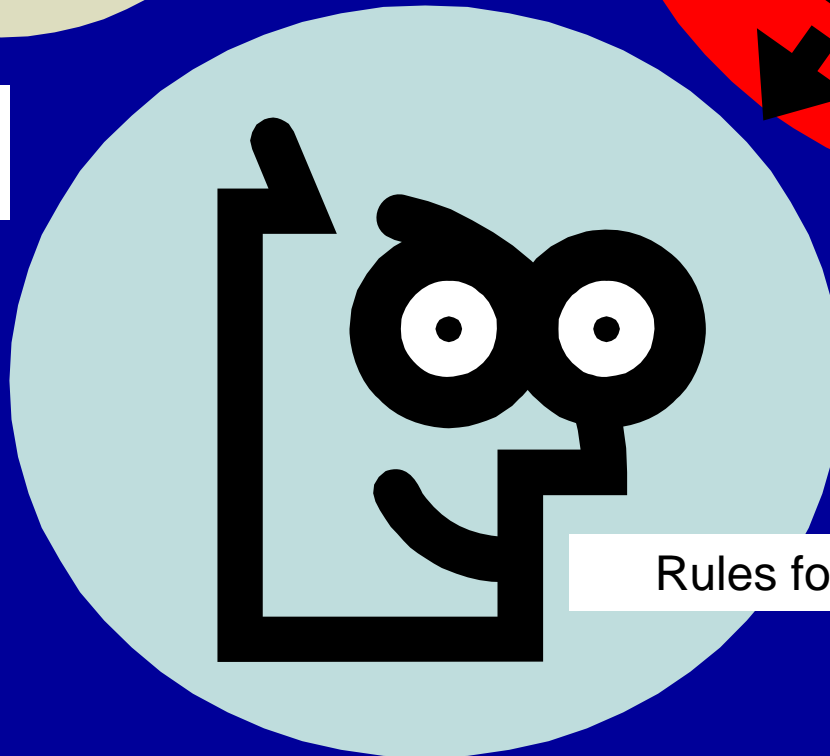
Rules for ME



Rules for being a
Wife



Rules for being a
Caregiver



Rules for ME

Finding balance



Identity Rules

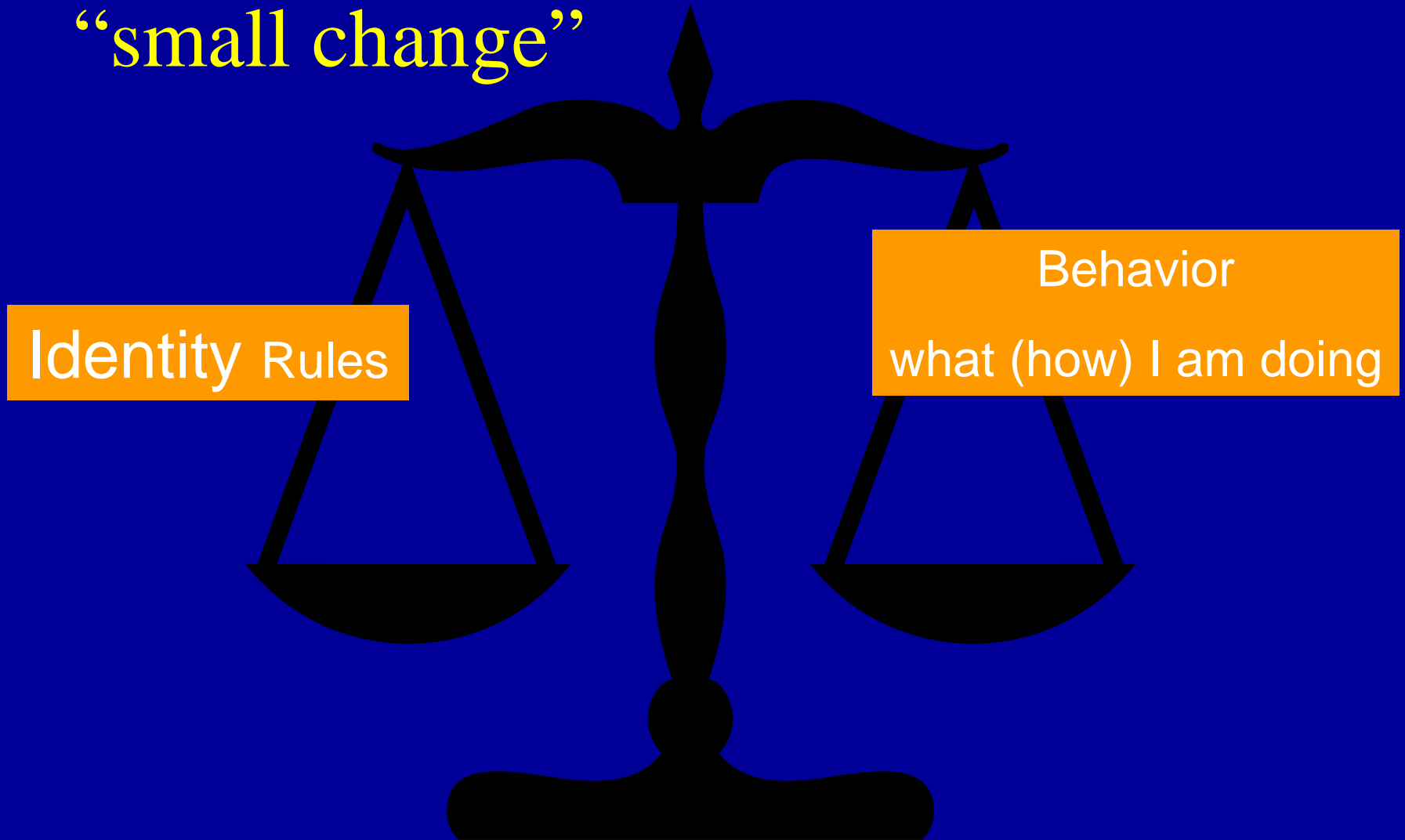
Behavior

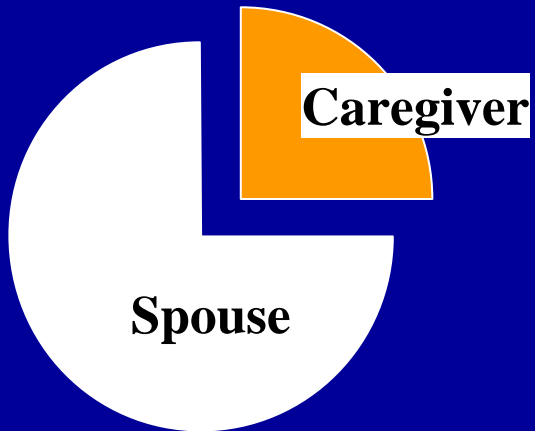


**Caregivers experience distress when –
their appraisal tells them that there
incongruence between
behavior & personal identity rules.**

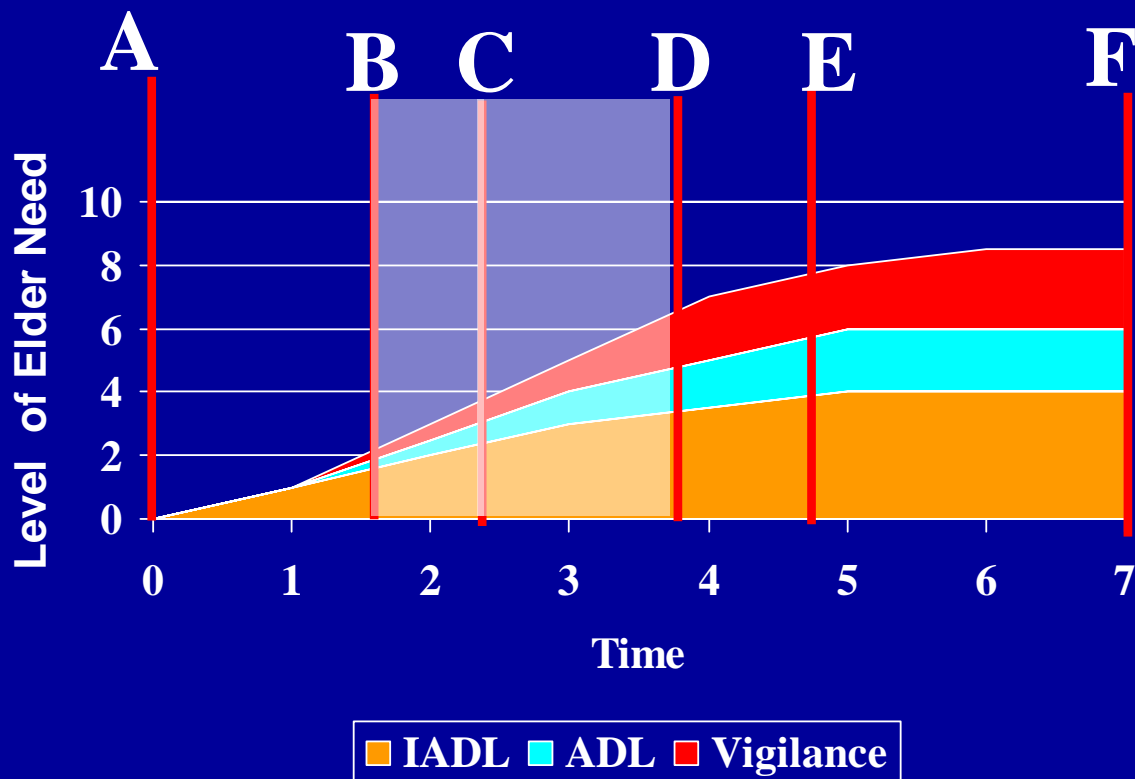
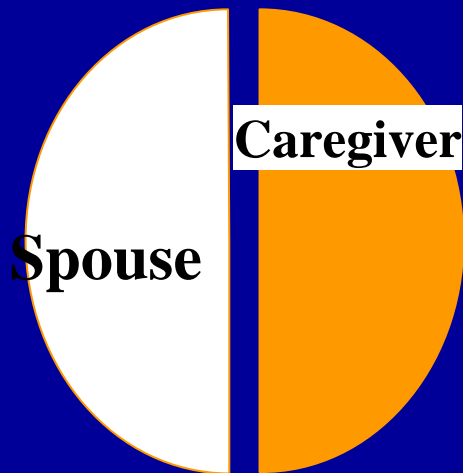
Finding balance:

Change with “Big CHANGE ” or
“small change”

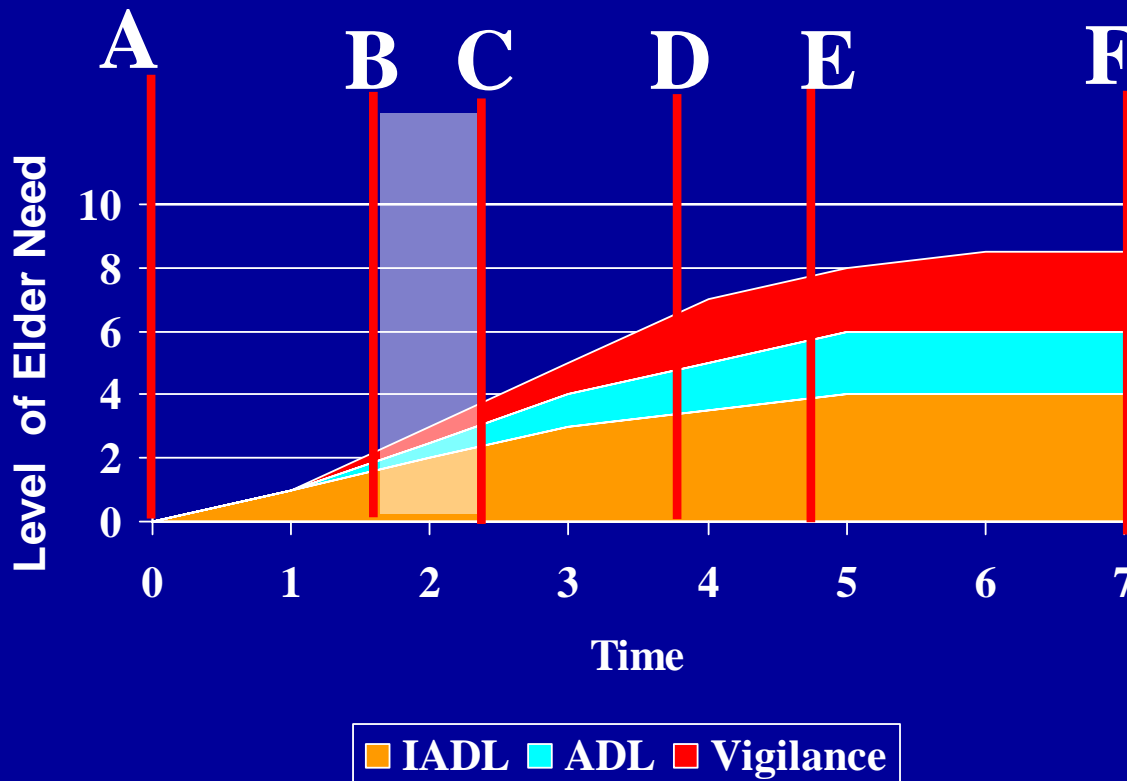
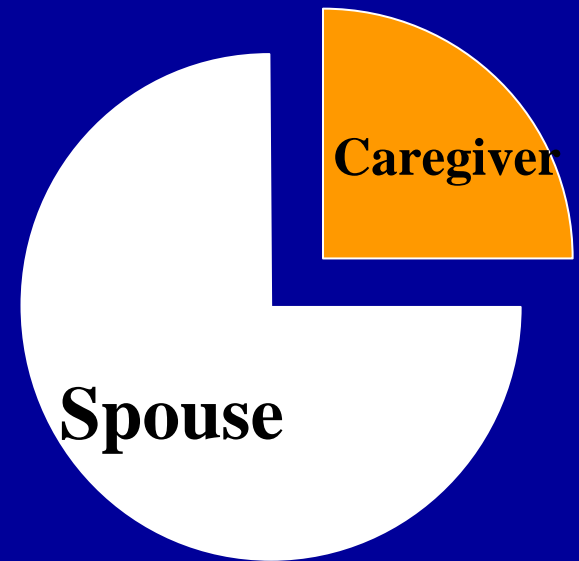




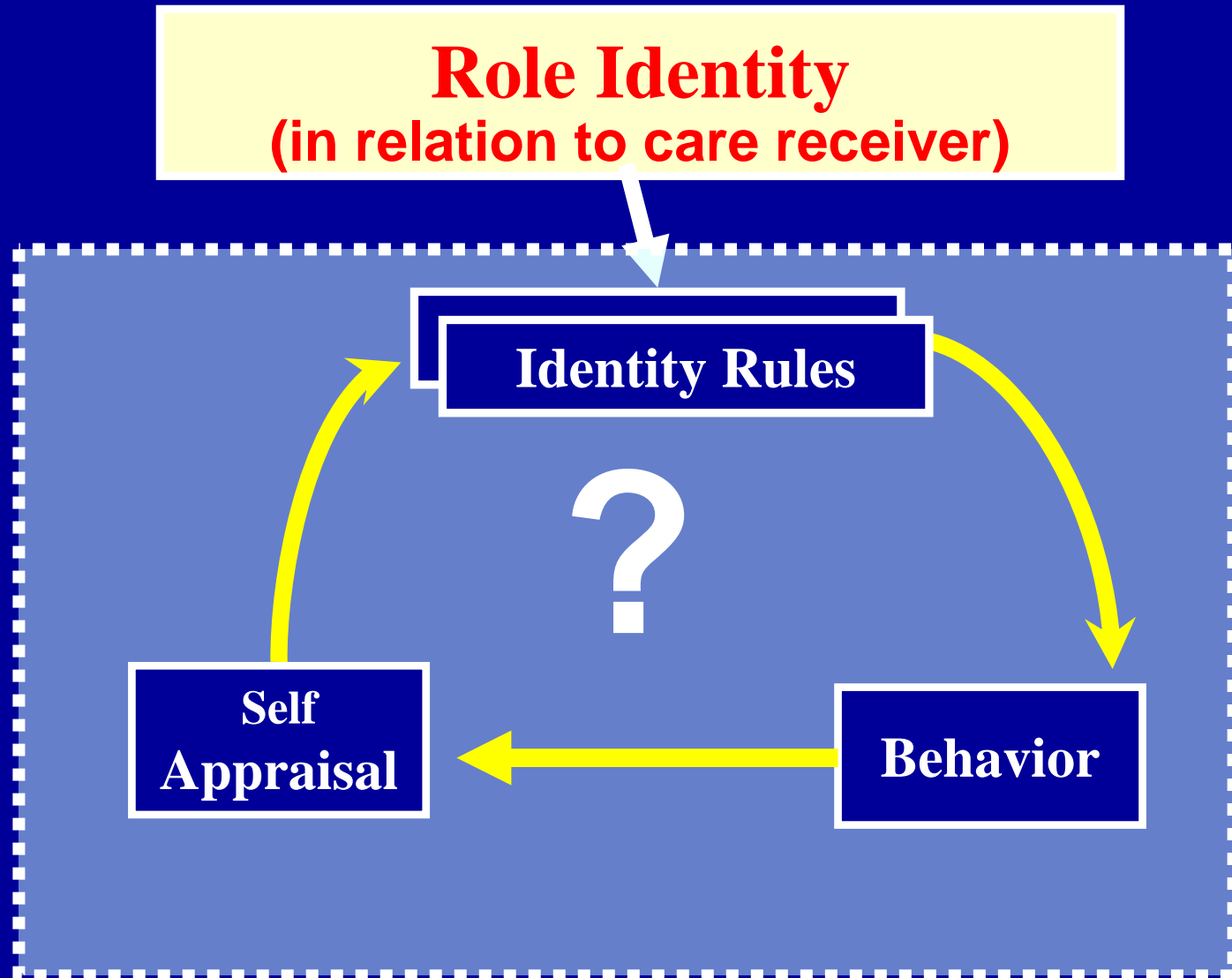
Big C?



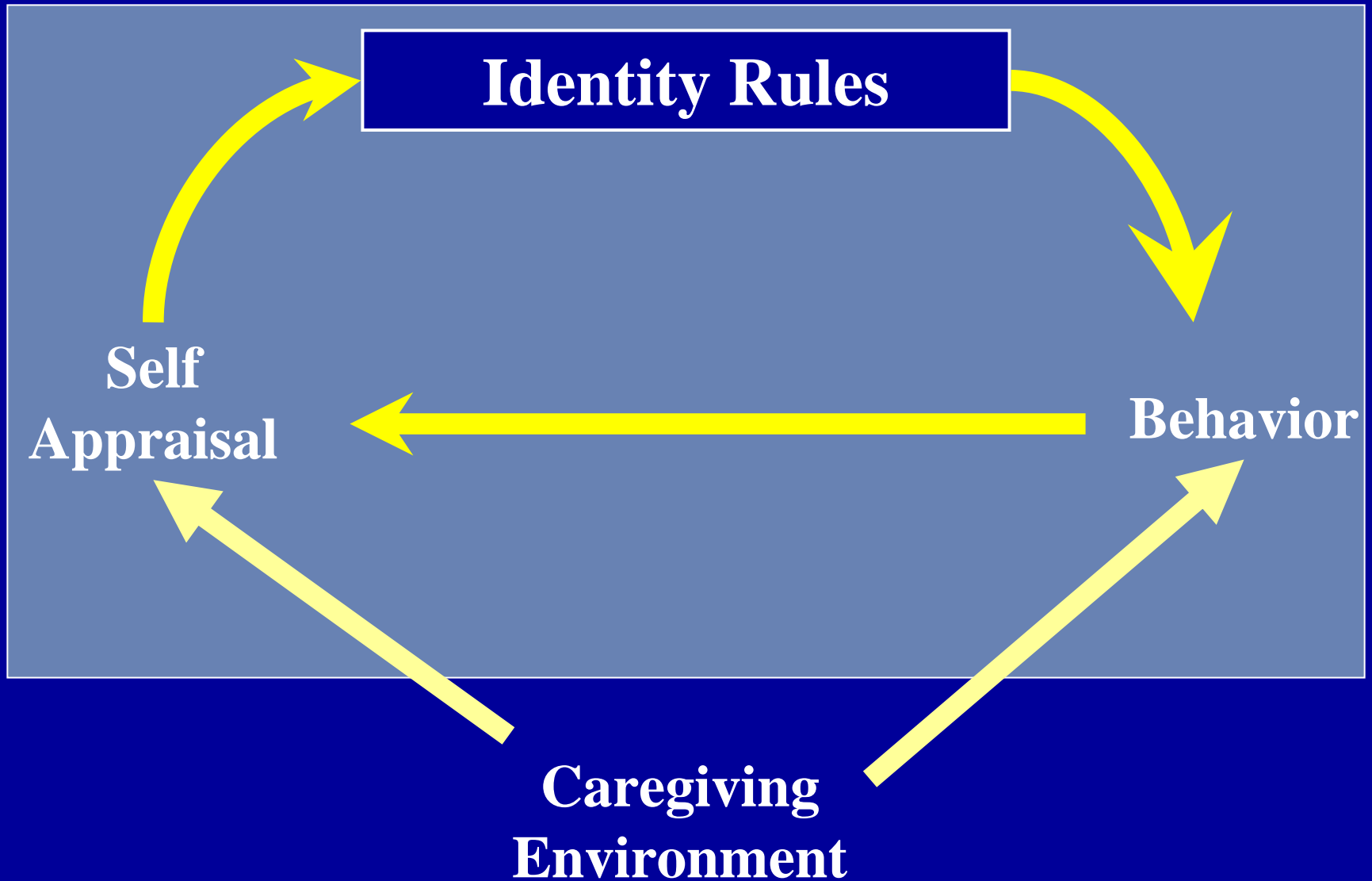
Maintenance of Identity within a phase.



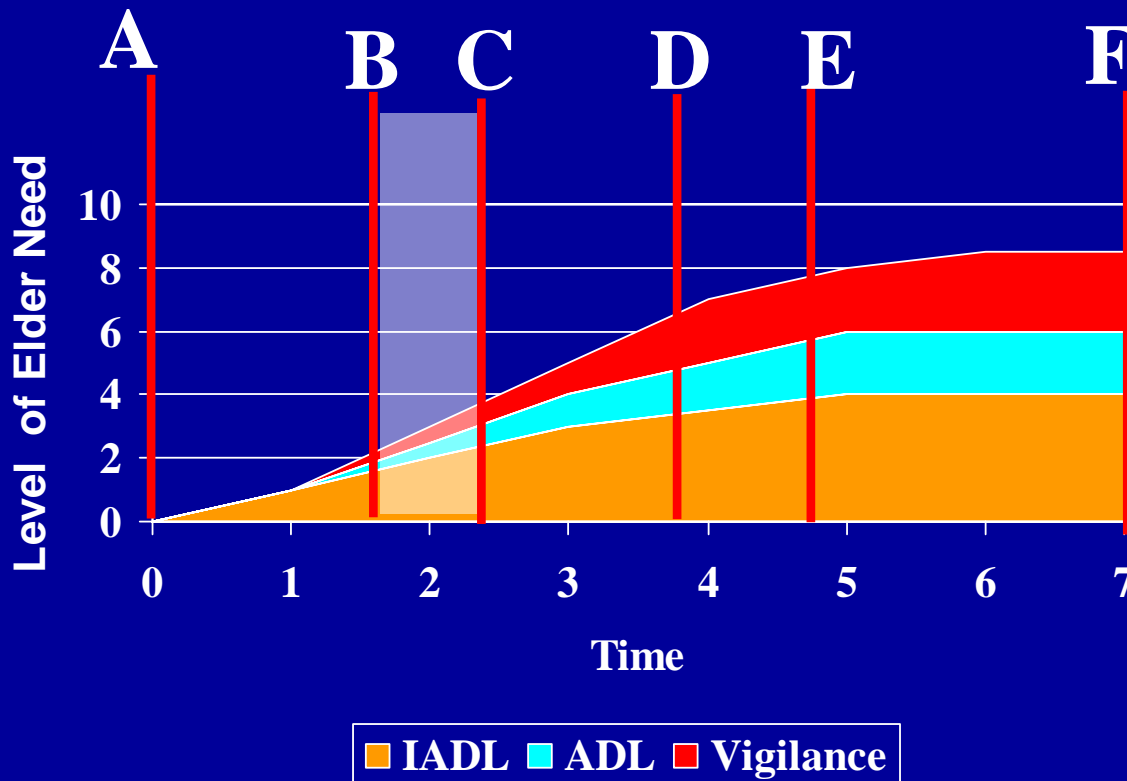
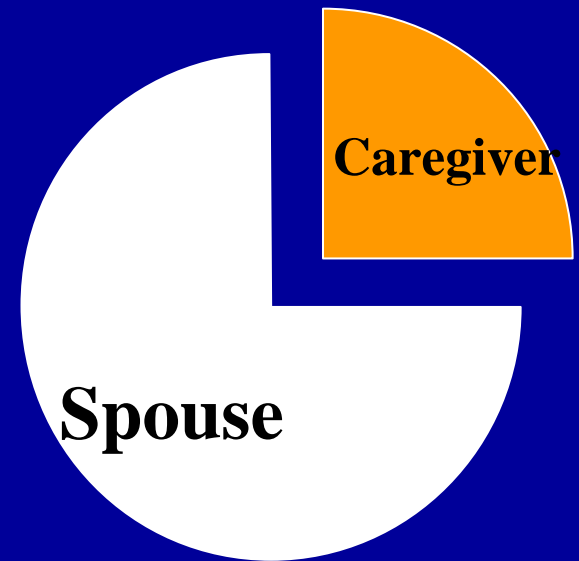
Identity Maintenance Process



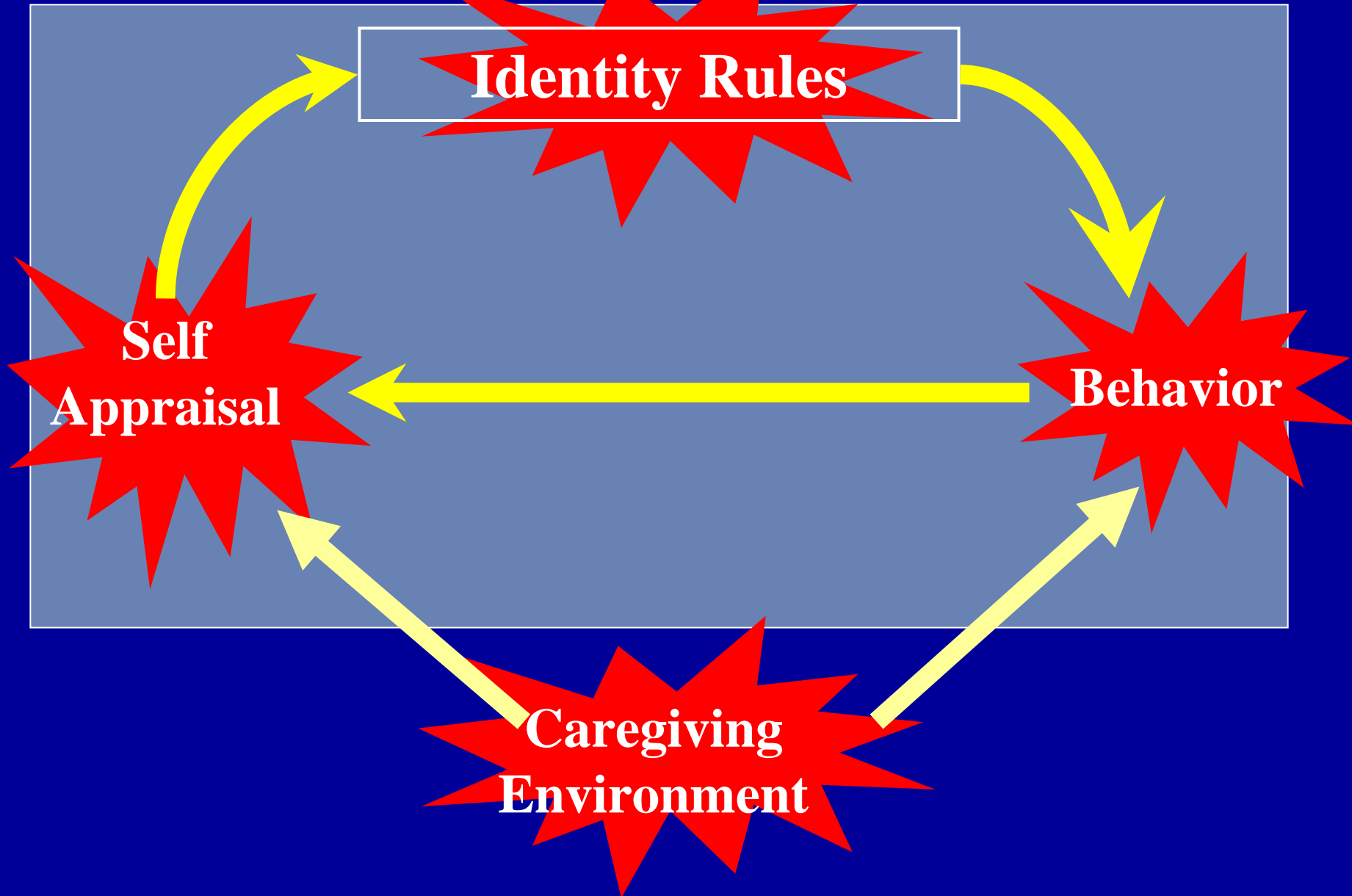
Disturbance of the Identity Maintenance Process



change as a adjustment
(change with a small “c”).



Disturbance of the Identity Maintenance Process



Part III

Rethinking Support Services

Rethinking Support Services

- Identify the *goals* for intervention
- Identify most effective *strategies*
- *Ask:* Which services are *consistent* with strategies and will help meet these goals?

Implications for Selecting Services

Set the Goal for intervention

1. Maintain Identity
2. Increase Caregiver identity
3. Reduce Caregiver Identity
4. Reduce Depression (the Symptom)

Pick Strategies

1. Change Rules
2. Change behavior
3. Change Appraisal
4. Change the Reaction (reduce the symptom)

Intervention Strategies

Identity Rules

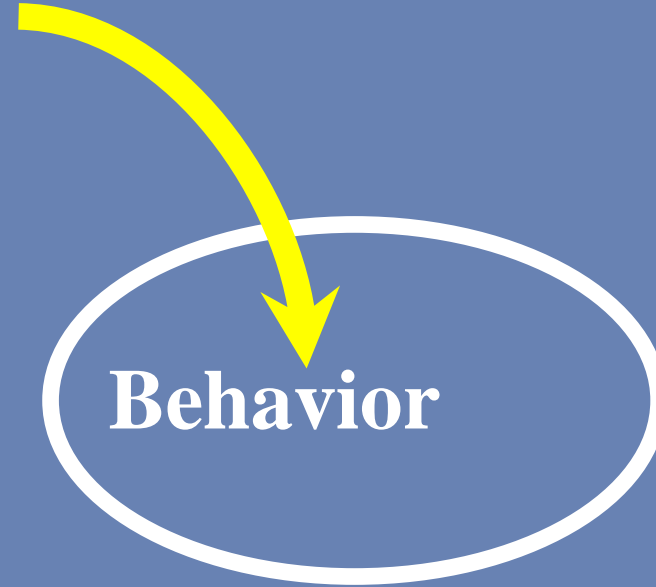
Strategy A: Change or adjust rules

1. Education about:
 - Disease Process
 - Caregiving Journey
 - Loss and Grief
 - Understanding Difficult behaviors
2. Counseling
3. Support Groups

Intervention Strategies

Identity Rules

1. Make less difficult
 - Teach CG Skills
 - Teach CR Skills
 - Assistive technologies
2. Introduce alternate sources
 - Adult Day care
 - In-home services
 - Informal Help
3. Alternate Care Setting
 - Assisted living
 - Nursing Homes



Strategy B: Reduce Workload

Intervention Strategies

Identity Rules

Self
Appraisal



1. Counseling

- caregiver journey
- family relationships & communication
- Resolving guilt feelings

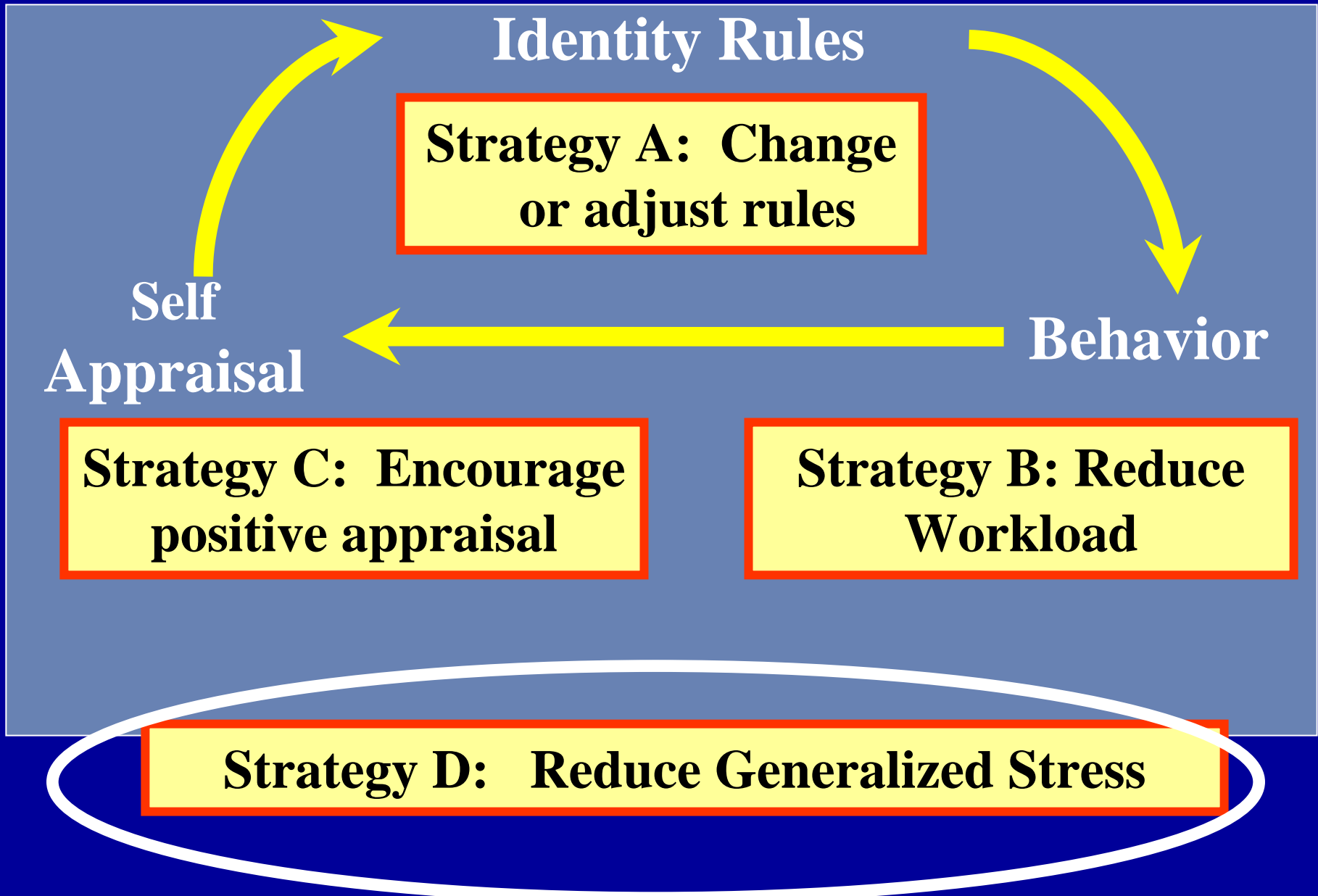
2. Education

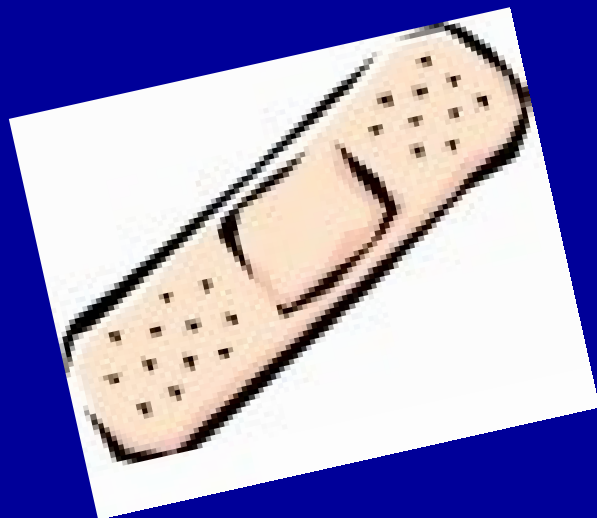
- caregiver journey
- cognitive reframing

3. Support groups

**Strategy C: Encourage
positive appraisal**

Intervention Strategies









1. Make less difficult
Teach CG Skills
Teach CR Skills
Assistive technologies
2. Introduce alternate sources
Adult Day care
In-home services
Informal Help
3. Alternate Care Setting
Assisted living
Nursing Homes

Strategy D: Reduce Generalized Stress

Support Strategies

- A: Change Rules  • Identity Standard
- B: Reduce Workload  • Behavior
- C. Support positive Appraisal  • Change Appraisal
-
- D: Reduce stress  • Reduce symptom

Typical Tool Box for Intervention

- Education Programs
 - Information
 - Skills
 - Emotional/ Psycho-educational
- Support Groups
- Counseling
- Respite
- Case Management



Targeting Interventions

- **What to target**

- Identity Discrepancy?
- Objective Burden
- Relationship Burden
- Stress Burden

- **What do we change?**

- Behavior
- Self-Appraisal
- Rules

- **Choice of Support Service**

- Education
- Support Group
- Counseling
- Adult Day Care
- In-home Support
- Assistive Technologies
- Informal Helpers

Education Programs

- Information to help change Rules
 - Disease Process
 - Caregiver journey/ identity change
 - Understanding loss and grief
- Education to reduce stress
 - Cognitive reframing
 - Coping skills
 - Stress management
- Teach or improve care skills
 - Direct care skills
 - Responding to difficult behaviors



Support Groups



- **Change source of appraisal (new sources)**
- **Help re-interpret appraisal**
 - Of other care receiver
 - Of other family members
- **Teach about sources of help (to lower task demands)**
- **Help change the Identity Standard**
 - (incorporate caregiver tasks into current identity)
- **Reinforce transitions**
 - (Give permission to change identities or reject role)

Counseling

- Changes identity standards
- Re-interpret appraisals
- Facilitates shift to New Identity
 - (new standards)

Respite: Positive

- Reduces work load
 - Substitute for caregiver
 - Change context
- Helps merge care role into primary identity (e.g. wife, daughter)
- Reduces Objective Burden

Respite: Negative When

- Negative appraisal from respite workers
- Negative appraisal from kin
- Creates work

Part III: UCARE

Uniform Caregiver Assessment & Referral

CARE MANAGEMENT USER MANUAL

- Evidence-based process that is:
 - Grounded in the *Caregiver Identity Theory*
 - Reflects current knowledge of research about caregiver interventions.

Characteristics of Good Assessment

1. Captures the full range of differences among family caregivers
2. Is sensitive to change
3. Easy to use
4. Understandable – to client & to care manager (transparent)
5. Instructive – Care manager knows how to use the information to guide practice

UCARE- an Assessment Process

- Core Assumption: Matching services to needs leads to:
 - Correct service at the correct time
 - Compliance with suggested care plan
 - Greater potential for positive impact
- Assumes transparency & Client Choice
- Provide insights about caregiver's context
 - Identifies strengths & challenges
 - Types and Sources of Burden/Stress
 - Appropriate Goals
 - Strategies (not services)
 - Options
- A wide array of services are useful and available to support Caregivers
- Not all communities have all services.

How to implement the UCARE process?

Four steps for working with family caregivers

- Step 1: Assessment of Caregiver Needs
- Step 2: Interpretation of information to determine type and level of need
- Step 3: Identify goals, support strategies and services
- Step 4: Family consultation to develop a care plan

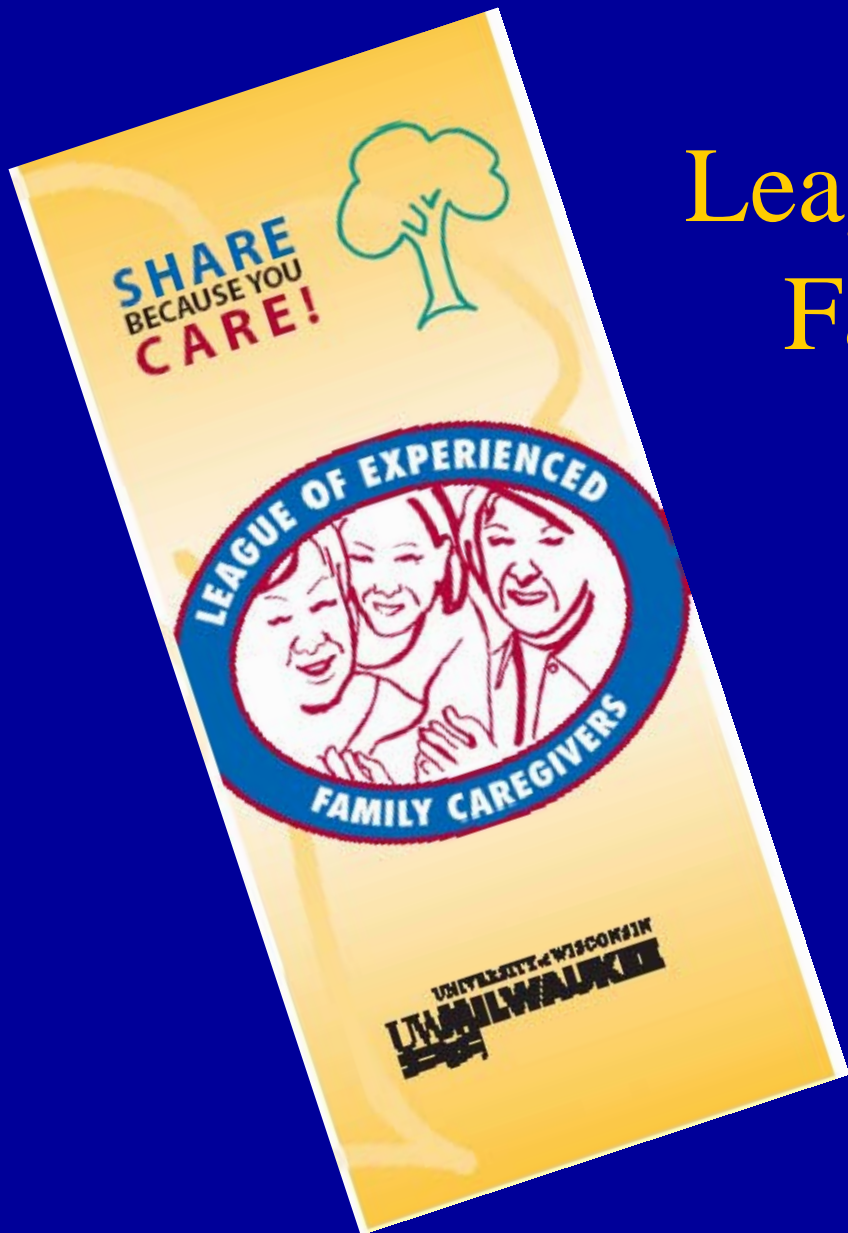
Tools for Implementation

- 1. Caregiver Screening Tool**
- 2. Caregiver Assessment Form**
- 3. Assessment Summary Sheet**
- 4. Service Selection Maps (five maps)**
- 5. Guide for Selecting Support Services**
- 6. Care Plan Form**

Benefits of UCARE

- Uniform Assessment
 - Guarantees equal opportunity for caregivers to obtain help
 - Not dependent on individual care managers' knowledge
- Informs Intervention & Care Plans
 - Focus on prevention – not crisis
 - Focus on strategies not services
- Provides Guidance for Planning
 - Helps identify service gaps
 - Helps identify new resources
 - Guides allocation of resources

League of Experienced Family Caregivers (LEFC)



Seeking the Wisdom of
Family Caregivers

www.familycaregivers.uwm.edu

Domains to be Measured

- Caregiver Status:
 - Length of Caregiving
 - Phase of Caregiving
 - Intention to Place
- Caregiver's Obligations
 - Hours of Care
 - Number of Other Dependents
 - Employment Status

Domains (continued)

- Caregivers Emotional & Physical Status
 - 3 measures of stress and burden
 - Identity discrepancy measures
 - Depression
 - Caregiver Health
 - Caregiver Uplifts
- Caregiver Resources
 - Informal supports
 - Income

Domains (continued)

- Care receiver Status
 - Functional level (ADL/IADL)
 - Problem Behaviors
 - Diagnosis
 - Memory problems

For Example

19. As a result of assisting the care receiver, have the following aspects of your life changed?

Have your caregiving responsibilities....	Not at all	A little	Moderately	A lot	A great deal	R	O	S	U	
(a) increased attempts by your relative to manipulate you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	5				
(b) decreased time you have to yourself?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		2			
(c) created a feeling of hopelessness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>			4		
(d) given your life more meaning?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				2	
(e) increased the number of unreasonable requests made by your relative?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	5				
(f) kept you from recreational activities?	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>		3			
(g) made you nervous?	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>			3		
<i>Have your caregiving responsibilities....</i>										
(h) made you more satisfied with your relationship?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				2	
(i) caused you to feel that your relative makes demands over and above what he/she needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	4				
(j) caused your social life to suffer?	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>		3			
(k) depressed you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>			4		
(l) given you a sense of fulfillment?	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>				3	
(m) made you feel you were being taken advantage of by your relative?	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	3				
(n) changed your routine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>		4			
(o) made you anxious?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>			4		
(p) left you feeling good?	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>				3	
<i>Have your caregiving responsibilities....</i>										
(q) caused conflicts with your relative?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	4				
(r) given you little time for friends and relatives?	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>		3			
(s) caused you to worry?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>			5		
(t) made you enjoy being with your relative more?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				2	
(u) left you with almost no time to relax?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>		3			
(v) made you cherish your time with your relative?	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>				3	
	(1)	(2)	(3)	(4)	(5)	Total	21	18	20	15

Easy to Interpret

Scale Score

	21	18	20	15
Total				

Page 5

- Transfer information to *Assessment Summary Sheet* to interpret score

Transfer Scores

Assessment Summary Sheet						
Section 1: Caregiver Status						
	Q					
Caregiver Phase	18	1=Phase I <input type="checkbox"/>	2=Phase II <input type="checkbox"/>	3=Phase III <input type="checkbox"/>	4,5=Phase IV <input type="checkbox"/>	
Intention to Place	16	Yes <input type="checkbox"/>		No <input type="checkbox"/>		
		16 = probably would or definitely would or have already been placed		16 = definitely not or probably not		
Section 2: Caregiver Emotional Needs						
	Q	High	Med	Low		
Relationship Burden	19	11-25	6-10	5-5		
Objective Burden	19	19-30	11-18	6-10		
Stress Burden	19	14-25	9-13	5-8		
Uplifts	19	17-30	10-16	6-9		
Depression-CESD	20	22-40	16-21	10-15		
Discrepancy	15	19-36	12-18	6-11		
Section 3: Care Receiver Needs						
	Q	High	Med	Low		
ADL	28	14-24	8-13	6-7		
IADL	28	32-40	25-31	10-24		
Problem Behaviors	14	11-45	3-10	0-2		
Memory	30	Yes <input type="checkbox"/>		No <input type="checkbox"/>		
		1 = yes medically diagnosed 2 = probable, but not diagnosed 3 = memory or cognitive suspected		0 = No		
Section 4: Caregiver Obligations						
Caregiver Obligations		High	Med	Low		
Personal Care Hours	12a	=>26	10-25	0-9		
Household Care Hours	12b	=>30	13-29	0-12		
Other Types assistance Hours	12c, 12d	=>15	5-14	0-4		
Employment	9	<input type="checkbox"/> Full Time	<input type="checkbox"/> Part Time	<input type="checkbox"/> None		
Total Dependents	10	Adults:		Children:		
Section 5: Other Useful Information						
Availability of family, friends, or neighbors						
Formal services currently in place						
Special circumstances						
Client ID #		Caregiver Name				
Date		<input type="checkbox"/> Initial / <input type="checkbox"/> Follow-up				

Assessment Summary Sheet

Section 1: Caregiver Status

	Q				
Caregiver Phase	18	1=Phase I <input type="checkbox"/>	2=Phase II <input type="checkbox"/>	3=Phase III <input type="checkbox"/>	4,5=Phase IV <input type="checkbox"/>
Intention to Place	16	Yes <input type="checkbox"/>		No <input type="checkbox"/>	
		16 = probably would <u>or</u> definitely would <u>or</u> have already been placed		16 = definitely not <u>or</u> probably not	

Section 2: Caregiver Emotional Needs

	Q	High		Med		Low	
Relationship Burden	19	11-25	21	6-10		5-5	
Objective Burden	19	19-30	18	11-18		6-10	
Stress Burden	19	14-25	20	9-13		5-8	
Uplifts	19	17-30	15	10-16		6-9	
Depression-CESD	20	22-40		16-21		10-15	
Discrepancy	15	19-36		12-18		6-11	

Section 3: Care Receiver Needs

**Interpret
Score to
Determine
Need**

Guide for Choosing Service Selection Map

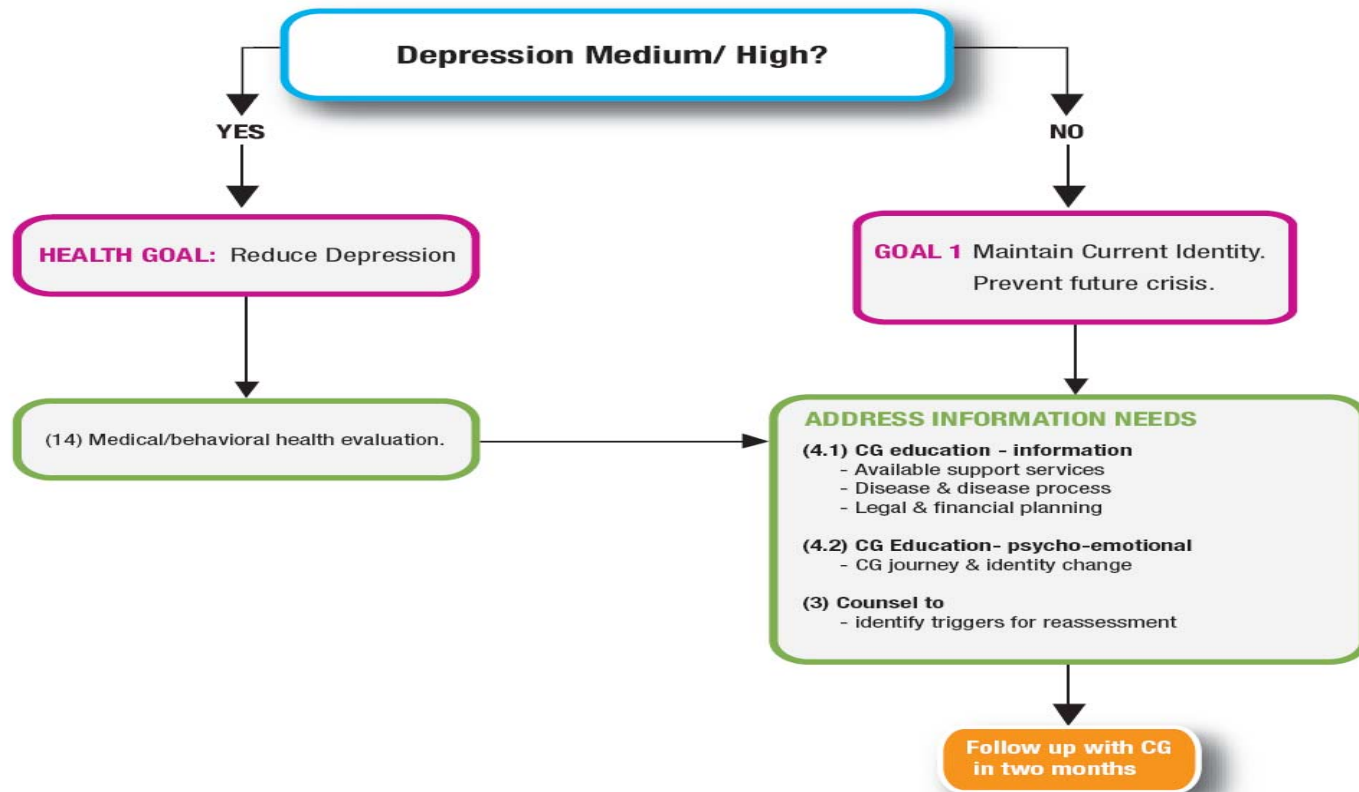
To select the correct service map, use the *Caregiver Assessment Summary sheet* to interpret the three caregiver burden scores and determine whether the caregiver intends to place the care recipient in an alternative care setting or leave the caregiving role in the near future.

Burden Scores	Map
All 3 Burden Scores Low	A
All 3 Burden Scores Medium or High with no intention to place	B
All 3 Burden Scores Medium or High Intend to place in near future	C
Relationship & Stress Burden Medium or High	C
Objective Burden Medium or High & Relationship Burden Low	D
Stress Burden ONLY Medium or High	E

Service Selection Map A

Use for Clients when **ALL Burden Scores are Low**

Caregivers with low scores on all types of burden tend to be individuals in early phases of the process and are often seeking very specific information. It is unlikely that these caregivers will have high depression scores. It is important to connect with these caregivers to prevent crisis in the future. [Caregiver group: 1]



Ucare

Uniform Caregiver Assessment and Referral
User Manual

Guide for Selecting Support Services

Rhonda J. V. Montgomery, Ph.D.



Guide Heading

Guide for Selecting Support Services	Goal 1: Maintain Identity						
Type of Service Program	A. Strategies to change personal rules for care (Adjust rules)	B. Strategies to reduce or minimize work load			C. Strategies to support positive self-appraisal (<i>Enhance or affirm current identity and behavior</i>)		D. Strategies to reduce generalized stress
		B1. Reduce care needs of care receiver	B2. Reduce difficulty of care and tasks	B3. Introduce alternate source for care to provide respite	C1. Stop negative self-assessment of role	C2. Reinforce positive aspects of identity	

Guide for Selecting Support Services		Goal 1: Maintain Identity					
Type of Service Program	A. Strategies to change personal rules for care (Adjust rules)	B. Strategies to reduce or minimize work load			C. Strategies to support positive self-appraisal (Enhance or affirm current identity and behavior)		D. Strategies to reduce generalized stress
		B1. Reduce care needs of care receiver	B2. Reduce difficulty of care and tasks	B3. Introduce alternate source for care to provide respite	C1. Stop negative self-assessment of role	C2. Reinforce positive aspects of identity	
(1) Adult Day Service (Experience time away from care responsibilities and reduce workload)							
a. Health model				XXX			
b. Social model				XXX			
(2) Assistive technologies (To promote functional abilities of care receiver and/or prevent injury)							
a. Emergency response system.			XXX				
b. Home Modifications (e.g. ramps, walk in showers, grab-bars)			XXX				
c. Install safety features to house (e.g. locks for cabinets or doors, lighting)		XXX					
d. Obtain care aids (e.g. beds, wheel chair, commode, adaptive or protective garments)			XXX				
(3) Counseling (Develop new perspective and practice skills with feedback)							
a. Alternative ways to express anger and frustration	XXX				XXX		XXX
b. Build sense of mastery and confidence					XXX	XXX	
c. Caregiver journey/identity change	XXX						
d. Cognitive reframing	XXX				XXX	XXX	XXX
e. Family communication and relationships	XXX				XXX		
f. Resolve feelings of guilt	XXX				XXX		
g. Self care techniques	XXX						XXX
h. Stress management techniques							XXX
i. Understanding loss and grief					XXX		
(4.1) Education for caregiver to obtain information about services and assist with planning for the future							
a. Available support services and how to obtain them			XXX	XXX			
b. Disease and disease processes (provide basis for accurate assessment of care needs)	XXX						XXX
c. End-of-life care and decisions	XXX						
d. Legal, financial and/or health care planning	XXX						XXX
e. Safe-guarding your family member and home (wander alert services; personal/home safety tips)		XXX					
f. Select suitable living environment			XXX				

NEXT STEPS

- Using and Testing Full UCARE Process
- Grant Applications

Seeking Partner Organizations

- Commitment at all levels of organization
- 4 to 6 care managers
- Commitment to training 2 to 3 care managers
 - 2-day intensive
 - 1 follow-up
 - Technical assistance consultations
- Use with 3 to 4 caregivers
- Share assessments & care plans for one year

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