Caregivers as Partners and Clients of Behavioral Health Services

OLDER AMERICANS
Behavioral Health
Technical Assistance Center

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Welcome and Overview

Introductions & Welcome

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Objectives

→ Describe caregivers in the U.S.: their numbers, who they are, what they do, impact of caregiving, and what is known about caregivers caring for persons with mental illness

→ Discuss strategies for reaching and engaging caregivers as well as assessing and referring caregivers to mental health services

→ Describe evidence-based interventions that impact caregiver issues such as depression, anxiety, anger, coping skills and problem solving

→ Discuss practical approaches for working with caregivers to address: decisions about where to focus, family interface with service systems and interpersonal conflicts within the family

→ Provide information about caregiving resources

Presenters

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Caregiving in the U.S.: The Numbers

→ 65.7 million people in the U.S. reported being a family caregiver in 2009.[1]

→ Provide 80% of the long-term services and supports in the U.S.

→ Valued at $450 billion[2]

→ 43.5 million care for someone 50+ years of age[3]

→ 14.9 million care for someone with Alzheimer's disease or other dementia[4]

→ Trend: Increasing numbers and situations

Caregiving in the U.S.: Who they are

→ A lifespan issue

→ Predominantly female (66%)[5]

→ Average age: 48[6]

→ But we are also seeing -

- Increasing numbers of men as caregivers

- "Sandwiched" generations

- Grandparents and kinship caregivers

- Families of wounded warriors

Caregiving in the U.S.: What they do

→ Occasional assistance to full-time care
→ "Whatever it takes"
→ Can include tasks ranging from simple to complex:
  - Transportation
  - Bill paying
  - Household cleaning/maintenance
  - Personal care
  - Medication management
  - Wound care and complex medical tasks
→ Spend an average of 20.4 hours per week providing care[7]

Caregiving in the U.S.: The impacts

→ Physical, emotional, financial & social stresses

→ Numerous studies show varying degrees of negative impact on physical and emotional health

→ Women more likely to report high stress due to caregiving[8]

→ Caregivers who experience social and emotional burden are at risk for problematic alcohol use[9]

→ Caregivers of those with emotional/mental health problems more likely to report health decline (28% vs. 12%)[10]

Mental Health Problems in the U.S.: Prevalence & Impact

→ Estimate: 26.3% of adults 18+ have a diagnosed mental illness which results in a disability[11]

→ 6% of these adults have serious mental illness[12]

→ Leading cause of disability among those age 15-44[13]

→ Impacts health, interpersonal relationships, marriage, employment, and family life

→ Costs approximately $193 billion in lost wages[14]

Caregivers of Persons with Mental Illness

→ A growing issue

→ Shifting policies over 60+ years

→ More direct roles for family caregivers

→ 32% of family caregivers care for someone with emotional/mental health concerns[15]

→ Multiple family members as caregivers

→ Rapidly changing needs and situations

Caregivers of Persons with Mental Illness

➔ Burden: *Objective* vs. *Subjective*

➔ Objective

- Family relationship disruption
- Economic issues
- Caregiver health impacts
- Systems navigation – finding help

➔ Subjective

- Psychological/emotional stresses[16]

Caregivers of Persons with Mental Illness

→ Key caregiver needs/concerns

- Symptom management [17]
- Care recipient treatment plan adherence[18]
- Finding and accessing specialist services
- Accessing other HCBS (e.g., respite)
- Obtaining financial assistance
- Locating and using therapeutic services[19]

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Caregivers as Clients of Behavioral Health Services

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TODAY'S TALK

➜ How to get them in the door—overcoming barriers to providing support services to family caregivers

➜ How to assess how well they're coping

➜ How to get them to help themselves—overcoming reluctance to reach out for and accept support

➜ When and how to refer to a mental health specialist

"I'm an anxious wreck at work"

→ Don, 56-year-old, African-American man sent by his doctor for psychotherapy for anxiety and "career burnout"

→ Has worked for 21 years in high-volume, high-pressure job as bank administrator

→ But thinks constantly about his mother with COPD and depression, alone in her home

→ Calls her 5 times during course of each day and then visits her after work

BARRIERS TO CAREGIVER SUPPORT

➔ Embarrassed that he's anxious when it's his mother who's suffering

➔ Not sure what family caregiving is

➔ Thinks of himself as a son, not a family caregiver

➔ Has never heard of an Area Agency on Aging or family caregiver support program

➔ Mother wants no services because she doesn't like strangers in her home

➔ Won't agree to be treated for depression because it's stigmatizing

BARRIERS (cont.)

➔ If I refer Don to a AAA or a family caregiver support group (especially early on in his treatment with me), he won't go

➔ **How do we engage him in process of seeking support for himself and his mother?**
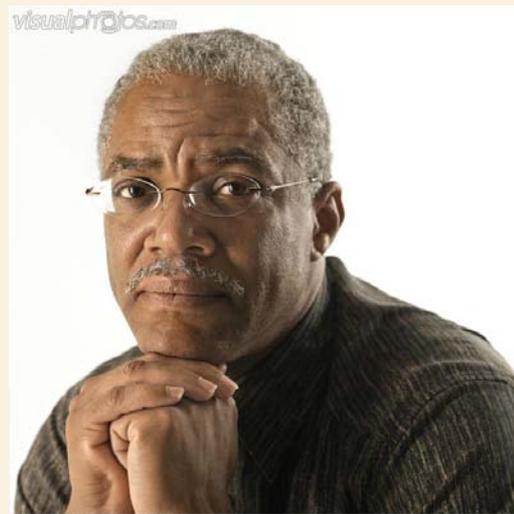
OUTREACH

To reach sons like Don, we have to go beyond advertising caregiver services. Two ideas:

1. Community events that define and normalize being a stressed-out family caregiver without being explicitly "caregiver" or "support" events

    Educational **sessions on taking care of an aging parent, (for National Family Caregivers Month?);   on disease specifics (e.g., COPD, depression) that also covers family impact**

OUTREACH (cont.)

2. Make greater use of primary care portal (and encouragement of medical specialists, too)

➔ **"Making the Link"—a National Association of Area Agencies on Aging program—some success but not lasting**

ASSESSMENT

→ Family Caregiver Alliance (2006):

→ http://www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf

→ 7 domains: context of caregiving; caregiver's perception of care recipient; caregiver's values and preferences; well-being of the caregiver; consequences of caregiving; caregiver's skills, abilities, knowledge; potential resources

ASSESSMENT

→ Qualls, <u>Caregiver Family Therapy</u> (2013):

→ "How would you describe your caregiving experience"

→ "Do you feel you can continue the current load of caregiving activities"

→ "How do you usually handle feelings of sadness and worry?"

→ "Do you spend time with friends or in social activities?"

ASSESSMENT (cont.)

→ Examples of formal instruments from APA Caregiver Briefcase:

→ Zarit Burden Inventory

→ Caregiver Self-Assessment Questionnaire

→ Perceived Support Scale

→ Perceived Benefits of Caregiving

Coping with Caregiver Stress and Burden

Caregivers' feelings of stress and burden can be assessed with standardized questionnaires and interviews. Although stress and burden are not diagnostic labels in and of themselves, they are key components of the profile of psychological distress experienced by many caregivers.

Tools for Adult Caregivers:

- Zarit Burden Interview
- Brief Measures of Secondary Role and Intrapsychic Strains
- Caregiver Self-Assessment Questionnaire
- Perceived Benefits of Caregiving

Coping with Caregiving

Caregivers develop coping strategies for the objective, as well as subjective, burdens of providing care. Some of these strategies are predictive of either positive resilience or poorer mental and physical health outcomes.

Measures for assessing Caregiving Coping include:

- Revised Scale for Caregiving Self-Efficacy
- Perceived Support Scale
- Picot Caregiver Rewards Scale
- Coping Health Inventory for Parents

Family Context

Tools for Parent Caregivers:

- Impact on Family Scale
- The Psychosocial Assessment Tool
- Parenting Stress Index
- Family Burden of Injury Interview

Assessment Issues

- Assessment Strategy
- Beginning Questions to Ask
- Assessment Tools
  Assessment Homepage →

In the Practice Section

- Common Caregiving Problems
- What do Psychologists Need to Know to Help Family Caregivers?
- How Caregivers Reach Psychologists
- Psychologists as Direct Service Clinicians and Consultants
- Conceptual Models
- Assessment
- Intervention
- Variations for Practice with Culturally Diverse Groups
- Business Pragmatics
- Common Ethical Issues
  Practice Section Homepage →

In the Caregiver Briefcase

- Caregiving Facts
- Practice
- Research
- Education
- Advocacy
- Resources
  Caregivers Briefcase Homepage →

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SELF-CARE

→ Caregivers are notorious for neglecting their own needs

→ Don would never have sought services if his physician hadn't twisted his arm and if he wasn't at risk of losing his job

→ Telling caregivers that taking care of themselves will better enable them to care for their loved ones is of limited effectiveness

SELF-CARE

→ Three ideas: Marathon Metaphor; Honoring the Mission; Receiving with Grace

→ Caregiving as marathon:

- Have to train to learn to pace oneself
- Have to learn the up-hills and down-hills of the lay of the land (disease)
- Have to learn to replenish along the way
- All are essential—or don't finish race

HONORING THE MISSION

→ Solicit the story of giving care

→ Avoid premature advice-giving

→ Inquire about meaning of caregiving in caregiver's life

→ Identify and honor the caregiver's sense of mission

→ Raise issue of sustainability

→ Inquire about sources of sustenance

RECEIVING WITH GRACE

→ Assumption: Most of us would rather give than receive

→ But running best race means taking in sustenance, utilizing support

→ Spiritual traditions of seeing giving in receiving—offering others the blessing of doing good

MENTAL HEALTH REFERRAL

→ Majority of caregivers will never need formal mental health services

→ Who does? Those who are so depressed, anxious, angry (abusive), guilty that it is affecting their capacity to function effectively and to provide adequate care

→ Issue of severity

REFERRAL (cont.)

→ "Caregiver burnout": dread, tension, irritability, anger, fatigue, sadness, disturbed sleep, difficulty thinking clearly and making decisions

→ Often a precursor to Major Depressive Disorder (MDD)

→ Don is anxious, distracted and jumpy all day long; fragmented sleep at night

REFERRAL (cont.)

→ MDD—sadness, lack of enjoyment, sleep and appetite disturbances, excessive guilt, low self-esteem, fatigue, difficulty making decisions, thoughts about dying; also anxiety, social withdrawal

→ Often disabling

→ Psychotherapy and drug treatments

REFERRAL (cont.)

→ Generalized Anxiety Disorder (GAD)—persistent, uncontrollable worry about a number of issues; muscle tension; sleep disturbance

→ Psychotherapy and drug treatments

REFERRAL (cont.)

➔ If possible, refer to caregiver-savvy, medically knowledgeable therapist

(e.g. APA's Psychologist Locator http://locator.apa.org/)

➔ If caregiver is reluctant to go to a mental health provider, urge visit to primary care doctor

➔ Broach mental health treatment as another strategy to strengthen caregiving capacity—run the best race

Caregiver Interventions

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The Case for Caregiving as a National Public Health Priority

Caregiving plays a unique and valuable role in our society. As the number of caregivers grows, the issues surrounding caregiving have gained national attention from a variety of sectors…National adoption of public health priorities is guided by specific principles *(Rao, Anderson, & Smith, 2002).*

These principles include large burden, major impact with respect to health costs or consequences, and potential for prevention.

CDC's *Assuring Healthy Caregivers* (2008).

Caregiving as a Health Disparity

→ **Hidden patients**
- **rarely assessed for health issues and needs**
- **often multiple roles while balancing health concerns**
- **lack time or energy for health promoting strategies**
- **significant gaps in the quality of their health and health care compared with noncaregivers**

→ **Disparities exist across groups of caregivers (e.g., race/ethnicity, gender, and spousal versus adult child)**

→ **Highlights the need for caregiver interventions**

Coon et al., 2004; Gitlin & Schulz, 2012; Haley et al., 2004; Gallagher-Thompson et al., 2010; Yeo & Gallagher-Thompson, 2006.

Chronic Stress Trajectory of Caregiving
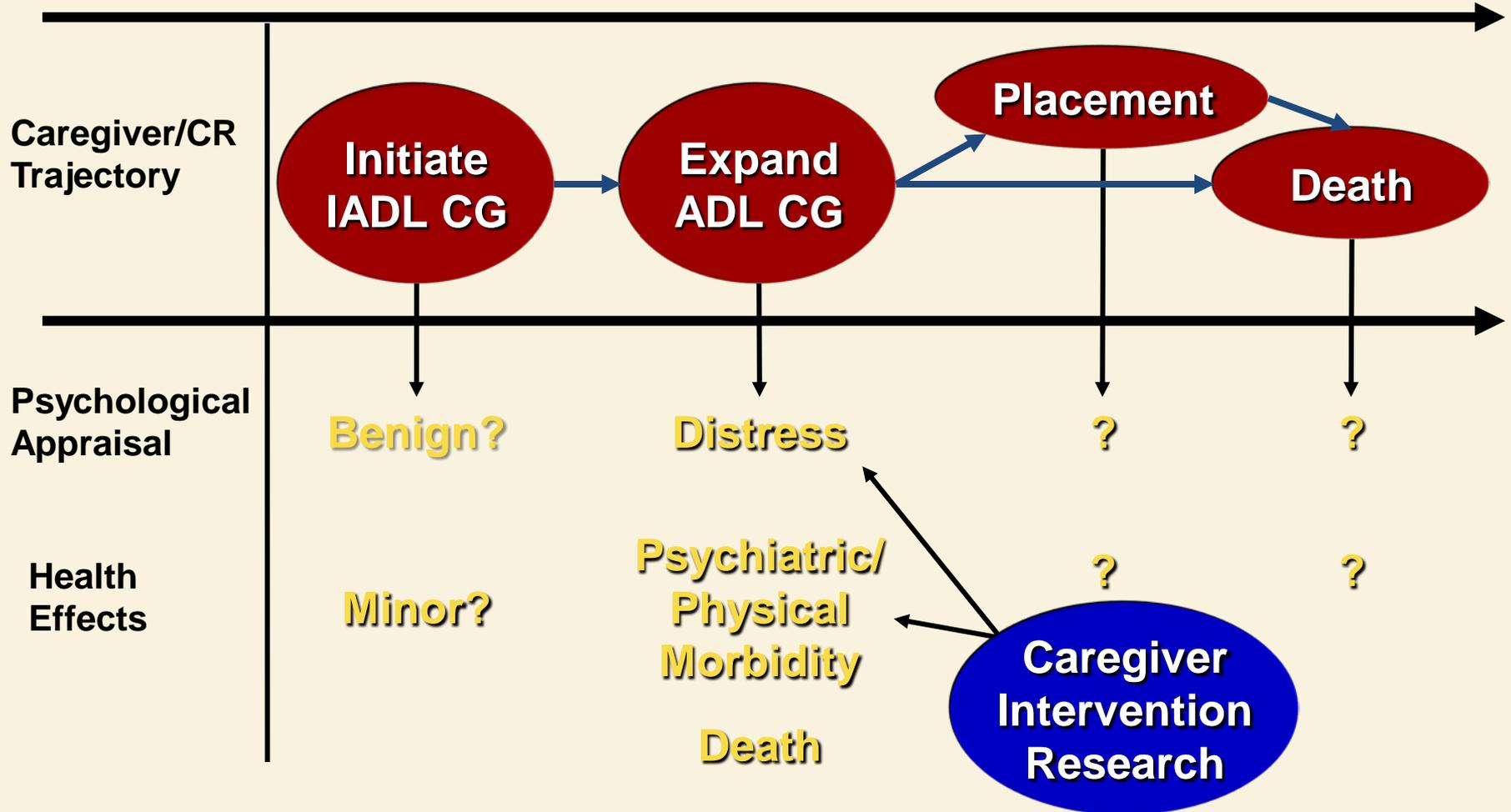
What's Successful?
Implementing Caregiver Interventions

→ **Education alone**

→ **Care Management**

→ **Respite**

→ **Support Groups**

→ **Environmental**

→ **Technological**

→ **Psychotherapy/Counseling**

→ **Psychoeducational Skill Training (CR, CG, both)**

→ **Multi-component**

Coon, et al., 2012; Coon & Evans, 2009;
Gallagher-Thompson, & Coon, 2007; Sörensen, Pinquart, & Duberstein, 2002

Psychotherapy - Counseling

→ Evidence for cognitive behavioral (CBT) approaches to reduce depression and anxiety. Monitor and change thoughts and behavior.

→ Screened for greater levels of psychiatric morbidity; therefore, more intensive. Offered either individually or in groups across 8-20 sessions.

→ More emphasis on development and use of therapeutic relationship than in psychoeducational skill building. On average, more therapists have advanced degrees.

→ Additional studies needed in this area. Preliminary evidence for brief psychodynamic approaches.

(e.g., Akkerman & Ostwald, 2004; Gallagher-Thompson & Steffen, 1994; Marriott et al., 2000)

Psychoeducational Skill-Training

→ Largest category. Various interventions with different focus or distress targets (e.g., depression management, anger management, care recipient behavior management)

→ Emphasize skill building
- Teach coping skills to manage emotional and/or behavioral problems (CR, caregiver or both)
- Basic support and education (caregiving and disease)

→ Examples include Savvy Caregiver, Progressively Lowered Stress Threshold Model, Coping with Caregiving

(Buckwalter et al., 1999; Gallagher-Thompson et al., 2003; Ostwald et al., 1999)

Alzheimer's Disease Supportive Services Program
Evidence-Based & Innovation Projects

Legend:
- ☾ 2007 Grantee
- ★ 2008 Grantee
- ☀ 2009 Grantee
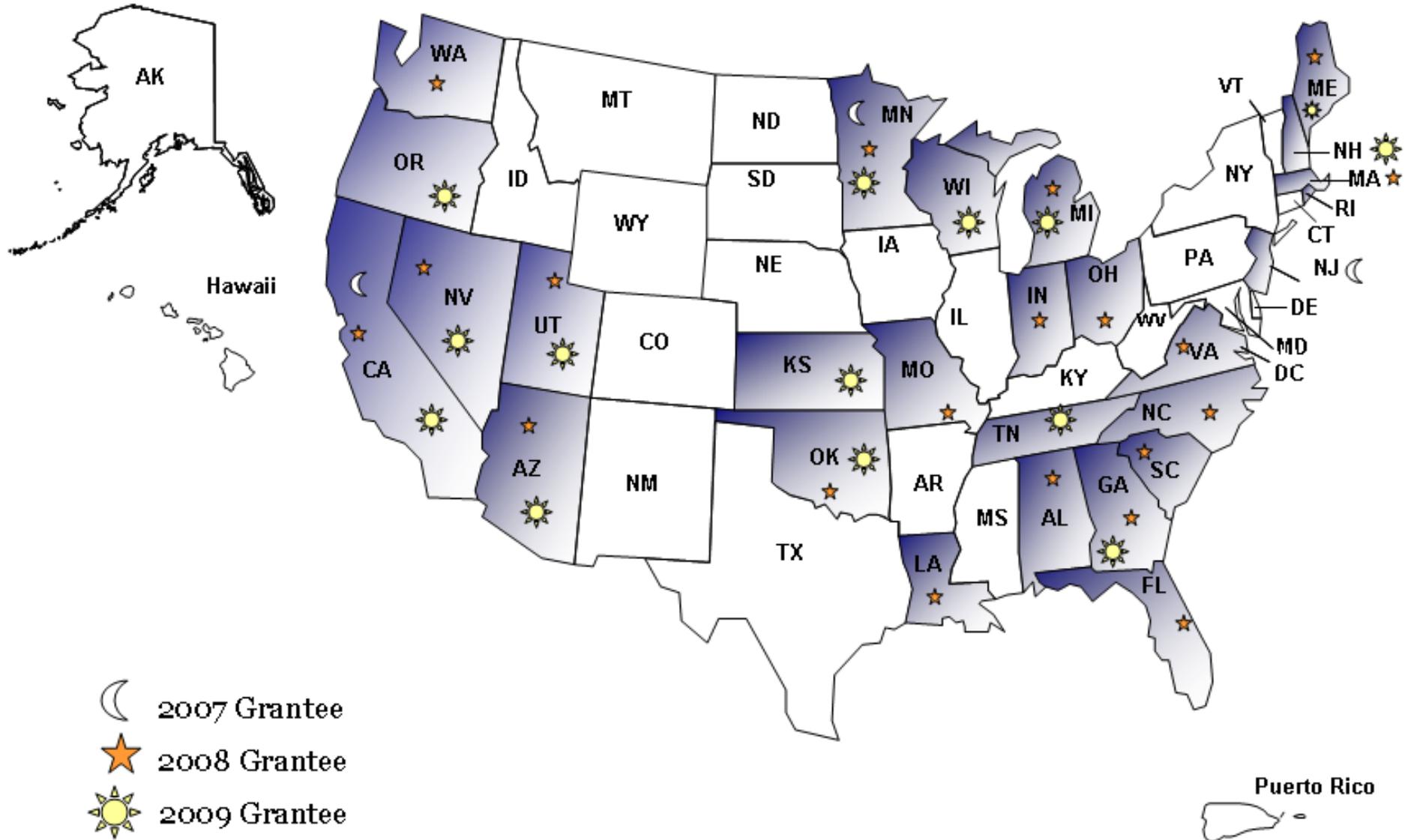
A Skill-Training Example:
CarePRO (Care Partners Reaching Out)

- **Alternating Skill-building Groups & Coach Calls (10 weeks)**

- **Built on *Coping with Caregiving***
  - Mood management, Stress management, Effective communication, TBR & Problem solving, Pleasant Events
  - Targets CWC's impact on depression, negative coping, negative interactions, positive coping

- **Partners**: Alzheimer's Association, Area Agencies on Aging, Arizona & Nevada state units on aging, ASU & CCLRCBH.

- **Chapter delivery to 600+ caregivers with Area Agencies assisting with respite.**

- **Well over 95% reporting overall benefit (85% benefited "a great deal"). Project still in progress; outcomes this summer.**

Multicomponent Interventions

➔ Incorporate two or more conceptually different approaches combined into one intervention package.

➔ Only 3 projects met this category, and thus warrant replication.

➔ Two of three are being translated as part of AoA's ADSSP Evidence-based Projects:

- NYU Caregiver Intervention & REACH II. (Belle et al., 2006; Mittelman et al., 2004)

NYU Caregiver Intervention

Enhanced Counseling & Support Intervention

Two individual and four family counseling sessions: teach ways to manage patient behaviors and/or promote family communication; provide education and community resources.

Ongoing support group for emotional support and education

Ad hoc counseling to help manage crises and various changes and transitions

Reduced depressive symptoms. Only study with long term follow-up (over 3 years); and, found impact on placement. (Mittelman et al., 1996; Mittelman et al., 2004)

REACH II Intervention

Multi-component in-home individual intervention: education, skill-training, telephone support groups, CTIS.

Addressed five areas linked to caregiver risk profile: 1) Safety Issues, 2) Social Support, 3) CR Problem Behaviors, 4) Emotional well-being, & 5) Self-care and Health Behaviors.

Hispanic and Non-Hispanic white REACH II caregivers showed greater improvement in quality of life indicator (depression, burden, social support, self-care, problem behaviors).

African American spouse caregivers also experienced greater improvement. (Belle et al., 2006)

Chronic Stress Trajectory of Caregiving

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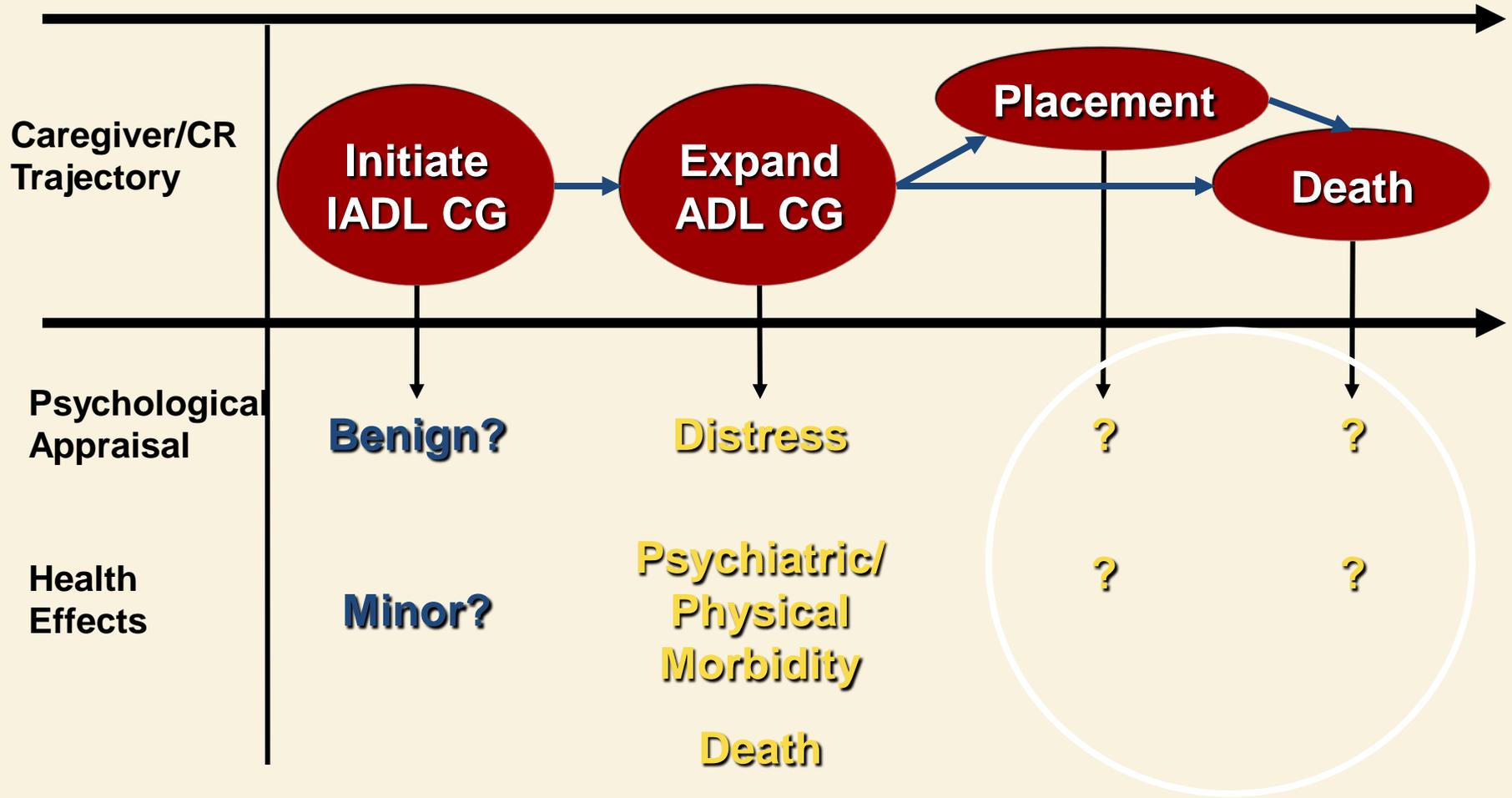
Caregiver Responses after Placement (REACH example)

➔ REACH: followed caregivers of care recipients placed in a long-term care facility within 18 months of randomization to a treatment; effects of placement transition

➔ No significant change in either depressive symptomatology or anxiety

➔ Depression was higher for caregivers who were married to the care recipient, visited more frequently, or were less satisfied with help received from others

➔ Anxiety was higher for caregivers who visited more frequently, or were less satisfied with help received from others

Schulz et al., 2004

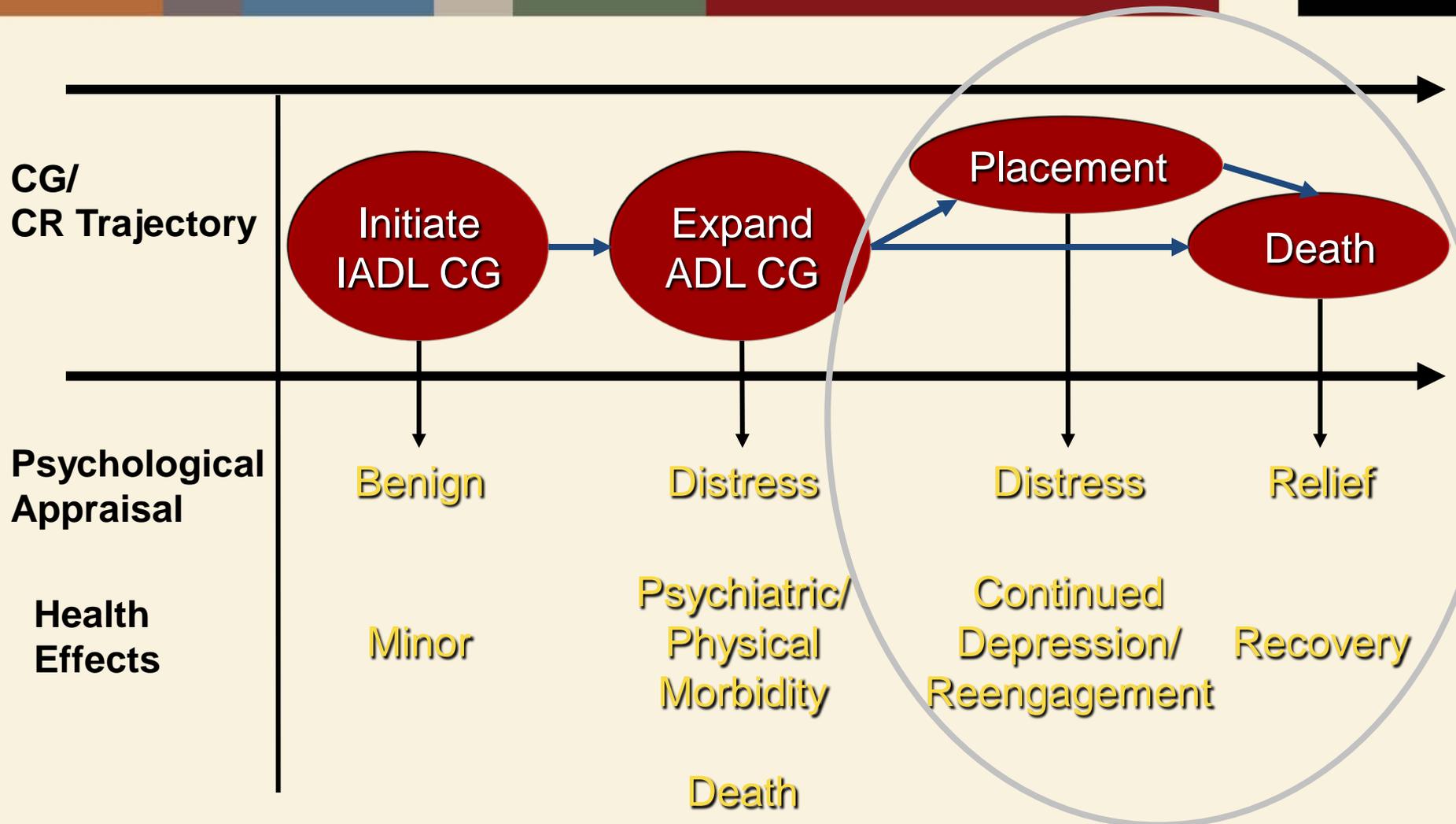# Caregiver Responses after Care Recipient Death: REACH & NYU

REACH

→ Significant declines in depressive symptoms (3 months); Substantially below caregiving levels (12 months).

→ Involvement in psychosocial interventions had an impact on complicated grief.

NYU Caregiver Intervention

→ Intervention participants reported fewer depressive symptoms after bereavement

(Haley et al., 2008; Holland et al., 2009; Schulz et al., 2003)

Chronic Stress Trajectory in Caregiving

CG/CR Trajectory	Initiate IADL CG	Expand ADL CG	Placement	Death
Psychological Appraisal	Benign	Distress	Distress	Relief
Health Effects	Minor	Psychiatric/Physical Morbidity Death	Continued Depression/Reengagement	Recovery

Family to Family for Older Adults?

→ Highly structured course lasting 2-3 hours a session for 12 weeks; offered by NAMI trained family members

→ Education (mental illnesses, medication, rehabilitation); problem-solving and advocacy skills; self-care and mutual assistance

→ Evidence for improved problem focused coping and knowledge about mental illness.

→ However, average age of family caregivers was 52 (60% were parents; 12% siblings; 10% spouses/partners).

Dixon et al., 2011

A Call for Multiple Levels of Intervention

➜ **Individual**

    I&R/Helpline, skill-building groups, psychotherapy

➜ **Interpersonal**

    Early stage groups for spouses

➜ **Organizational/System**

    HCO/CBO care pathway partnerships.

➜ **Community**

    Media campaigns or CCRC

➜ **Policy**

    NFCSP, AMA Caregiver Self Assessment Tool, Respite Tools

Coon, Ory, & Schulz, 2003

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Complicated Issues in Work with Caregivers

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Key Complications

➔ How do you decide where to focus?

➔ Family interface with service systems

➔ Interpersonal conflicts within the family

Where to Begin with CG?

→ Families don't use our language

→ Opportunity for engagement is brief

→ Consider the context of your encounter with CG – what is realistic?

- Listen for the focus of the story
  - CG distress
  - CR well-being
  - Care decisions
  - Cost to other family members
- Build an alliance over purpose/mission

CG Interface with Service Systems is Often Problematic

Different languages

Different frames

Ignorance of systems

Inevitably

Mutual blame
Disconnection
Added stress

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Family questions are practical….

➔ When should we be worried?
- How do you know when it is time to step in?
- How can I possibly know what really goes on?

➔ Is she really at risk?
- What if someone tries to take advantage of her?
- What if she falls and can't call us?

➔ I'm getting depressed
- When I can't do this anymore, then what?
- The doctors want me to take charge but it is his life…

➔ My _____ and I disagree –
- My sister thinks Mom should move but I think she needs to stay at home and get some help.
- My husband thinks we need to use "tough love" with our son, but I don't see how it helps him to be homeless.

Disconnect …..

Health System

- "Families can't be included because of HIPAA"
- "If the family was just taking better care, she wouldn't be so depressed."
- "Why won't the family let us do our job?"
- "The family needs to take charge here or he will never get his feet on the ground. They have to make him take his medicine."

Family Challenges

- "Why won't they talk to me…I'm the one who has to take care of her??"
- "Why didn't they tell me that _____ was an option?"
- "I just thought it was normal transitions."
- "They think I can just wave my hand and make him take his meds and go to work but he won't listen to me!"

Disconnect .....

Housing

- "Families want us to care for their loved one as if it was the only person we have."
- "Why can't the family just let us do our job?"
- "I dread seeing her family come in because I know they will find something wrong to yell about"

Family Challenges

- "She is sitting for hours before they respond to her
- "Sometimes I think she is just a "bath" or a "feeding", not a person"
- "The staff seem to resent me being there"
- "No one seems to know what is going on"
- "All of a sudden they want to hospitalize her, and I had no idea this was coming."

Navigation Coaching

➔ **Service systems are complex and require support for successful navigation!**

- Multiple points of entry - Lack of clear triage point

- Lack of clear pathway through

- No single provider owns the problem

- Providers define their roles specifically; families view their roles as broader

Make it User-Friendly

→ Use *their* language

→ Offer clear pathways to help

- Location, clear expectations of available service, contact information

- Note what is NOT available in the way they hope

- Offer option to return if they lose their way

→ Offer strategies for success with CR and systems

- Focus on the practical

- Help with both the WHAT and the HOW

Address Interpersonal CG Conflicts

➔ **START: "What do you most want for the CR?"**

➔ Listen for the almost universal dilemma of "independence" and "safety" as guiding values

- Name the ambivalence as universal to family care across the lifespan

- Notice how various family members have become voices for one side or the other

- Normalize the interpersonal conflicts that arise because of that variation

- Emphasize valuing of the CR that is shared by family members

Long Family History…

➔ Relationships are decades old

- Today, often see the dynamics in place when everyone left home

- Personalities are relatively stable (unless cognitive impairment)

➔ But the focus is NOT on 10, 20, or 30 year old conflicts (typically)

Family caregiving is at the intersection of …
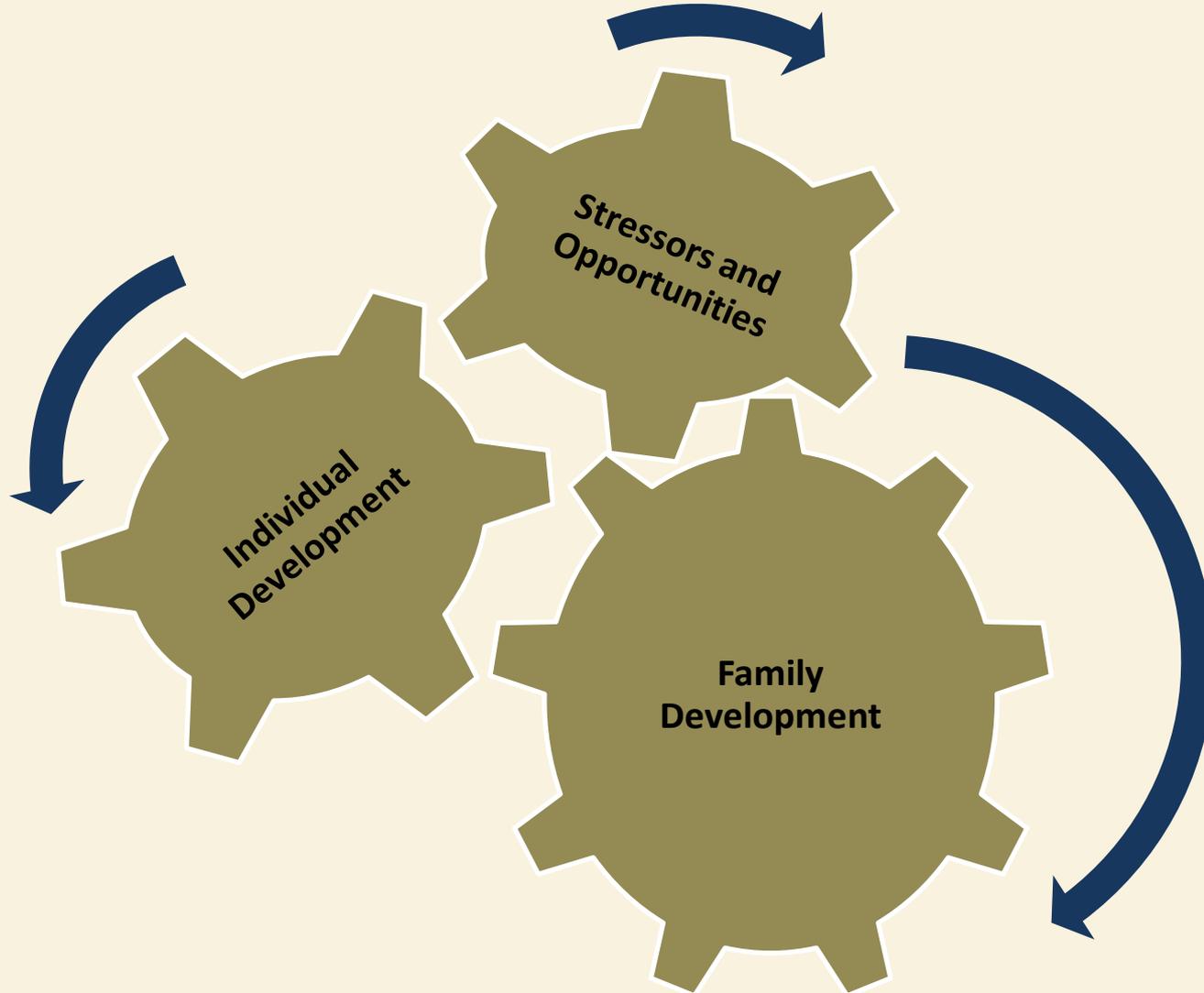
Widen the Lens

→ Look at how the CG's many roles may conflict

→ Map out the CG structures (who is doing what for whom)

→ Look at broader impact of CG structures on all family members

- How does CG role impact family members beyond the CG and CR? E.g., the teenagers in family? Elders?

- Whose development is at risk?

"The smallest change that will make a difference" may be the focus

→ Family conflicts

- 80-20 rule applies to CG too
  - Personality disorders
  - Long-term messy families
- Helping move in small steps
- Boundaries – what can/can't I do?
- Strategic interventions

More strategies to help…
Family Caregiver Briefcase

→ www.apa.org/pi/about/publications/caregivers/index.aspx

→ Resources to help you connect with caregivers, including

- Facts

- Practice

  – Assessment strategies

  – Intervention research

  – Models for intervention

  – Practical Issues

  – Ethics

- Advocacy resources

- Readings and online resources

The Current Family Caregiver Support Landscape

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The Current Family Caregiver Support Landscape

→ The National Family Caregiver Support Program (NFCSP)

→ Federal categorical funding streams (e.g., Medicaid Waivers)

→ Federal Demonstration Programs across age and disability

→ Veteran's and military programs

→ State-funded caregiver support programs

→ Lifespan Respite Care Program

The NFCSP: Overview

➔ Created in the 2000 reauthorization of the Older Americans Act (OAA)

- Title III E (NFCSP)

  http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx

- Title VI C – Native American Caregiver Support Program

➔ 2006 Reauthorization of the OAA

- Refined Targeting Criteria

- Modified Age Requirements

The NFCSP: Overview

→ Focuses on family caregivers as service recipients

→ Modeled on early state programs

→ Package of services known to be of greatest value to family caregivers

→ Built upon and integrated within the structure of the Aging Services Network

→ Formula grants to states – 70+ population

The NFCSP: Required Services

➔ Information

➔ Access Assistance

➔ Counseling; Support Groups; Training

➔ Respite

➔ Supplemental Services (on a limited basis)

The NFCSP: Partnering Opportunities

➔ The Aging Services Network

- State Unit on Aging
- Area Agency on Aging
- Local Service Provider

➔ Connections between Behavioral Health programs/providers and caregiver support programs

➔ State caregiver/respite coalitions

➔ Specialized support groups, training, caregiver education

Caregiving Resources

➔A caregiving resource list with links will be sent to all registrants after the webinar.

Questions & Answers

Please type your questions into the Webex Chat Box.

Thank You.