

# Welcome

## Webinar: Making Respite More Effective with Dr. Dale Lund

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This project is supported, in part, under a grant from the U.S. Department of Health and Human Services, Administration on Aging. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. These contents, however, do not necessarily represent the policy of the U.S. Department of Health and Human Services and endorsement by the Federal government should not be assumed.

# Presenter

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# Topics for Today

- Why do we need to focus on making respite more effective?
- Explain why respite has not yet been found to have “whopper” benefits to caregivers
- My suggestions for how to make respite more effective
- My suggestions for policy and future research and program evaluation

# Why focus on making respite more effective?

1. Enhance quality of life of caregivers, families and care recipients
  - ❑ 68% report caregiving as most stressful life experience ever.
  - ❑ Every aspect of a caregiver's life can be impacted by their experiences
  - ❑ Need much broader set of outcome measures to reflect this.

# Why focus (continued)

## 2. Accountability and future funding support

- ❑ Research-to-date shows inconsistent or only moderate positive outcomes
- ❑ (Why?)
- ❑ No “Whopper Effects” yet
- ❑ Will future funding be forthcoming?

# What do we already know about ways to make respite effective?

1. Begin using respite early in the “caregiving career”.  
(Too little, too late)
2. Use it regularly (scheduled)
3. Use it in sufficient amounts (dosage)
4. Use it along with other services  
(skills, education, emotional and social support, counseling, transportation, nutrition, leisure, etc)

\* Respite can be a multi-component intervention

# What else? What might be missing in studies of respite effectiveness?

Most caregivers are very satisfied with respite service providers.

- BUT -

46% report being only somewhat or not very satisfied with how they spent their respite time ! (53% of not employed, 40% of employed)

# Why dissatisfied with respite time ?

1. Poor advanced planning
2. Wasted time and opportunities
3. Too much time on obligatory activities
4. Inconsistency between desired and actual time use
5. Did things that created more stress

# Why is inconsistency problematic ?

When they are not satisfied with their use of time (also a discrepancy between “desired” and “actual” use of time) caregivers have been found to be:

- ❖ more depressed
- ❖ less satisfied with caregiving and
- ❖ more burdened (physically, socially, emotionally, lifecourse development, and time dependency)

# For the Family Caregiver

**To Access and  
Download:**

**<http://sociology.csusb.edu/docs/Respite%20Brochure%20%282010%29.pdf>**

# Multidimensional Types of Caregiver Burden

## 1. TIME-DEPENDENCE

Restrictions on Caregiver's time

## 2. DEVELOPMENTAL

Feelings of being "Off-time" in development relative to peers

## 3. PHYSICAL

Feelings of chronic fatigue and damage to health

## 4. SOCIAL

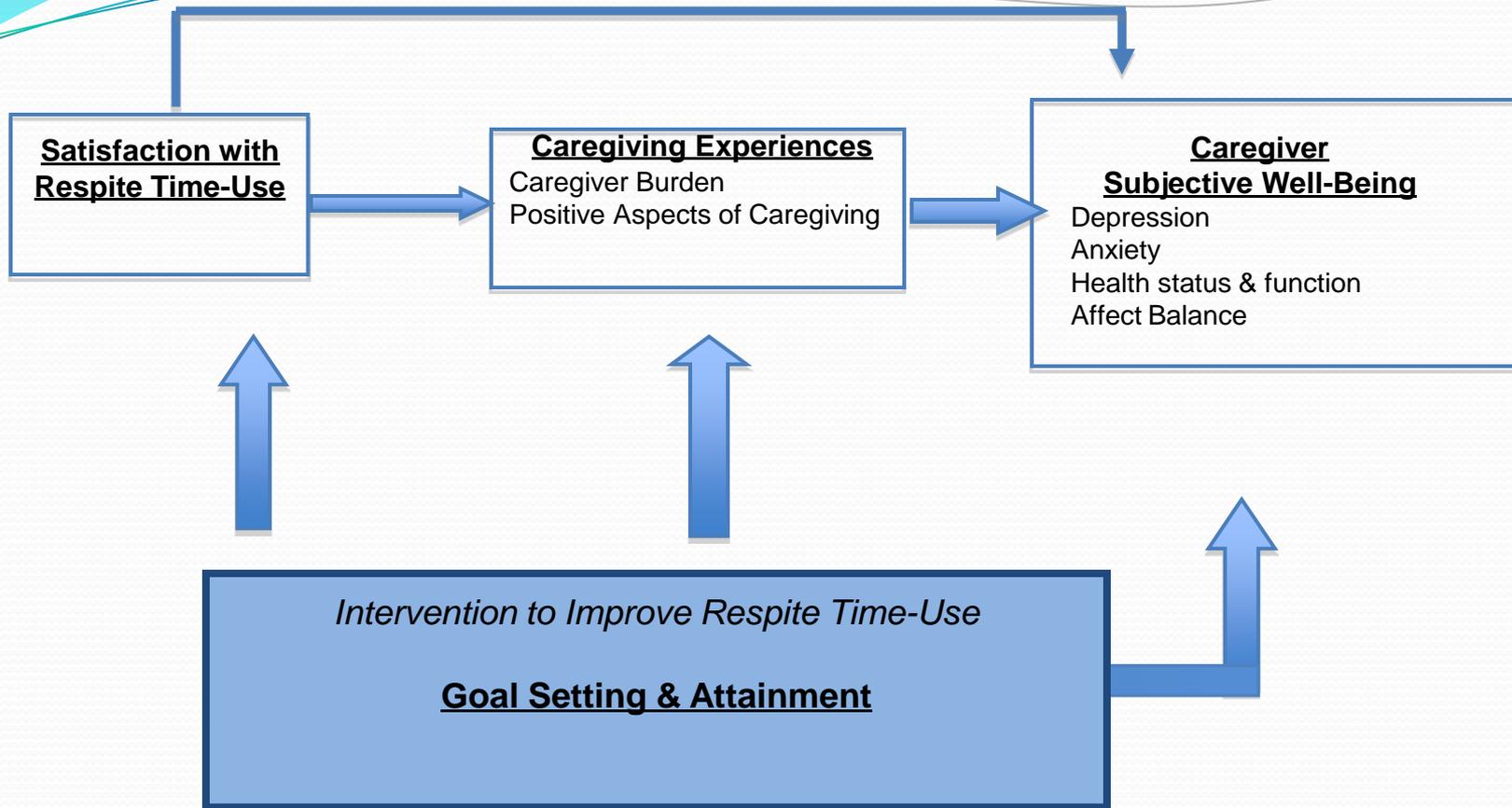
Feelings or role conflict

## 5. EMOTIONAL

Negative feelings like guilt, anger and resentment

\* Also important not to forget the possibility of satisfaction with caregiving

(Source: Novak & Guest, 1989)



**Figure 1. Conceptual Model: How the Proposed Goal-Setting Intervention Will Affect Caregiver Outcomes**

## **Need to include an examination of what caregivers do when they have respite time.**

- Are specific activities beneficial ?
- Amount of discrepancy between desired and actual use of time ?
- Degree of satisfaction with respite time ?
- Why not assess caregivers needs and desired continuity and set goals for respite time ?

# Continuity theory of life course aging

- Those who are able to maintain or continue engaging in their preferred and most meaningful activities (and values, beliefs, preferences) or minimize the most disruption to them will have more positive adjustments to aging
- Therefore, help caregivers by finding out what activities have they discontinued as a result of caregiving and encourage them to use respite to restore them or find substitutes. (This may require assistance from objective others at a distance)

# Selective Optimization with Compensation Theory

- Adjustments to life transitions often require individuals to be selective in what activities they pursue, find ways to optimize engaging in them while also recognizing the need to compensate for limitations beyond their control.
- Therefore, assist caregivers by helping them to be “selective” in identifying most desired activities to restore, “optimize” the activities by eliminating obstacles and finding facilitators but “compensate” by recognizing limitations out of their control. Do so through realistic goal-setting and attainment.

# Recommendations for Research & Evaluation on Respite

- Select broader range of outcomes
- Select more realistic outcomes
- Select outcomes that match program-specific goals
- Select outcomes targeted to individual caregiver needs (consumer directed)
- Focus on intervention studies
- Share findings with others
- Be more creative

# Outcomes to Consider

## Physical Health

exhaustion, days sick, doctor visits, exercise, nutrition-diet, subjective ratings, medications, improvements-declines in specific conditions, etc

## Mental Health

depression, anxiety, morale, subjective self-reports, satisfaction with daily life, etc

# Outcomes (continued)

## Situational

satisfaction with caregiving, perceived relationship with care-recipient, family relationships, work-related, use of other services, likelihood of institutionalization, etc.

Specific Program Objectives (goals of the service providers) identify outcomes to match each objective or goal

Goals of the Individual Caregivers (identify outcomes that match individual caregiver goals)

# Key Features for Respite Policy

- Enhance caregiver control over decision-making and use of service
- Enhance flexibility in services to match caregiver circumstances and preferences
- Enhance convenient access to services
- Enhance affordability of services
- View respite as a multi-component service (time to engage in other activities/services)
- Expect realistic and measurable outcomes
- Add an educational component to respite
- Encourage respite providers to share “best practices”

Live Questions (Type in Questions)  
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