

THE  
FREEDOM  
TRAIL  
TO  
RESPITE



15<sup>th</sup> National Lifespan Respite Conference  
October 15 to 17, 2013 ~ Boston

# Respite Reframed

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# The Journey

## *A Caregiving Trajectory: a crucible*

- ***Oblivion***: Teaching sociology – not aging but gender, globalization, ritual and performance studies
- ***Wake-up Call***: Introducing the world of dementia and broken systems
- ***Recovery through Action***: Innovative Planning and Development in Elder Services at a AAA/ASAP
- ***Now: Systemic Change through Leveraging Resources, Especially the Business Sector***: Partnering with organizations, growing supports for their employees and consumers.

# Influencing Factors

## *An American village family – of sorts*

- **Large, Irish Catholic family**
- **Core Values: family, religion, respect, love, and education**
- **Countercultural: all that matters is to be good and educated and all G-d will provide; non-materialistic**
- **Caregiving Modeled: grandmother died in my home; great grandmother died in her home**
- **Model's Challenge: I had a career and worked outside the home**

# Caregiving Choices

**Career:** Left my first tenure-track position in the Midwest to come home to be near parents, securing another tenure-track job at a local college

**Family:** Lived apart for two years with husband in Jakarta to stay near parents

**Home:** Purchased a home down the street from parents to keep them in their neighborhood and to facilitate ease for caregiving

# Vision

- **Parents remain in their house as long as possible**
- **Parents move to my house when they need more support**
- **Continue teaching with its flexible schedule and my ability to prepare classes at home with them**

# Reality

## **Them**

- **They refused to leave their home**
- **They refused support services**
- **Ultimately, they had to move into assisted living**
- **After fall and hip fracture, they had to move to nursing home**

# Decisions and Impact

## US

- **Juggled teaching, writing, conferences, and caregiving**
  - **A day in the life: broken hip, conference presentation, class using TA and Dean's response**
- **Took one year without pay using Family Leave Act**
  - **Returned to tenure's ultimate question: where is your book? "My parents are my book!"**

# Caregiving Structure

**Two of the six children shouldered the caregiving**

- **Daughter One: Casework**
- **Daughter Two: Financial and legal**
- **Supports: Few and far between**
  - **Counseling, spouse, daughter**
    - **Not work**
    - **Not faith community**
    - **Not parents' friends: fear, proximity**
    - **Little from other siblings: distance, emotional entanglements**

# The Journey's Skills Learned

- ***Advocacy*** – fighting right up to the end when told we didn't need hospice since they had everything on site
- ***Consumer Rights*** – firing the cardiologist, demanding testing (neurological), demanding stopping testing (bone cancer)
- ***Diplomacy*** – negotiating with siblings
- ***Self Care*** – counseling, gym
- ***Presence*** – stress reduction through letting go of past and future; rethinking respite from getting away to being connected
- ***Business Mindset*** – decisions: stewards of taxpayers money

# **New Perspective: CSR – a nation-wide respite movement opportunity**

- ***Lessons from the recent MBA Mexico Trip:***  
business in Latin America is imbued with a social responsibility ethos (religious and social justice influence)
- ***U.S.:*** businesses here are into CSR – corporate social responsibility and “giving back”
- ***Respite movement’s nation-wide opportunity:***  
branding respite to get buy-in and resources from corporate America so necessary as government resources grow scarce

# *Branding Opportunity*

- **Borrow a page from marketing and brand respite**
- **Mainstream it – grow awareness, develop a language for it and make it part of our vernacular**
- **Look to the business sector to partner for money and volunteers**
- **Define respite so that businesses and other community partners know it, *feel it*, and see it as familiar and as something they must have.**
- **Should be easy given the statistics on the caregiving cost to employers if they see it is affecting their bottom line**

# Personal Costs

- **Caregivers to persons age 50 or older spent an average of \$5,531 out-of-pocket in 2007.**
- **Long-distance caregivers spent \$8,728.**
- **37% of caregivers age 50 or older quit their jobs or reduced their work hours in 2007.**
- **Caregivers are more likely to suffer from depression or anxiety and have: long-term medical problems, weaker immune response to the flu and immunizations, slower wound healing, higher levels of obesity, and at risk for memory and mental health problems.**

*Sources: Office of Women's Health, US DHHS; AARP Policy Institute, Valuing the Invaluable*

# Workplace Cost

- *Fifty-nine percent of informal caregivers have jobs in addition to caring for another person. Because of time spent caregiving, more than half of employed women caregivers have made changes at work, such as going in late, leaving early, or working fewer hours.*
- **7 in 10 caregivers were working at some time while caregiving (2009)**
- **7 in 10 caregivers made cut back work hours, changed jobs, stopped working, took leave, or other changes**
- **66% had to go in late, leave early, or take time off in 2009**
- **78% of those caring for a child experienced at least one job impact...compared 68% for those caring for an adult age 50 or more.**

Sources: National Alliance for Caregiving in collaboration with AARP's, *Caregiving in the U.S. 2009*; AARP Policy Institute 2007; <http://www.womenshealth.gov/publications/our-publications/fact-sheet/caregiver-stress.cfm>

# Branding Challenge

- **Current usage sounds medical**
- **Many caregivers don't think they need it**
- **Many caregivers are proud or do not trust others to help**
- **Working caregivers don't want to jeopardize their jobs by sharing their caregiving demands with employers**
- **The community doesn't know what it means**
- **Others are simply unaware of invisible caregiving**

# **Respite – Government and Human Services Definition**

- **Coordinated systems of accessible, community-based respite services for all family caregivers regardless of age or special need.**
- **What does this formal definition mean? Does it speak to people? Do they understand the need in this definition?**

# Respite - Reframed

From 13<sup>th</sup> century Latin term, respectus

**Consideration**

**Recourse**

**Regard**

**Look at**

**See**

<http://dictionary.reference.com/browse/respite?s=b>

<http://www.myetymology.com/english/respite.html>

# **What would it look like to have respite integrated into our daily sites of activity?**

**Typically, respite provides isolated support for the isolated dyad: caregiver/recipient or for isolated family**

*In-home respite*

*Adult day-care centers*

*Short-term nursing homes*

*Day hospitals*

**Issue: not integrated into our daily activities and sites**

# **What if? An Invitation**

*What if caregiving were seen?  
What if caregiving were valued?*

**Seen and valued and supported in every institutional site  
and in all our activities:**

- Work Place**
- Faith Place**
- Shopping Place**
- Leisure and Travel Place**
- Book Clubs**
- Mass Audubon**
- Medical Place**
- Fitness Place**
- Special Interest**
- Appalachian  
Mountain Club**
- Others**

# Leveraging Resources

## Reducing Isolation

Bring caregivers and care recipients back into the fold but not artificially

- *Based on personal and family interest*
- *Day programs are artificial sites requiring a wide array of activities*
- *Imagine: Mass Audubon birding - integrated programs for caregiver and care recipient*
- *A program based on interests*

# **Requires a New Awareness A New Type of Assessment**

**Wherever we are, we ask:**

- Who is not here and why?**
- Who needs support so that they can participate?**
  - Ex. Ernie and dancing at festivals and family reunion**

# **Ex. Alaska – Cruise Place**

- **Alaska Story**

**Two old men in two different visitor centers waiting for their family waiting for family to return from day trips**

# Messaging

- **Caregiving is difficult and valuable work**
- **Caregivers deserve to be acknowledged and supported**
- **Their struggle and pain (laughter and joy) deserves a space**
- **Without it – beware – our businesses, our organizations, our communities will suffer because of caregiver stress**

# **Making Spaces for Respite Reframed Respite Regarded Making Spaces for Caregiver Stories**

## ***Ex. Partnering with Businesses***

- Do a survey monkey: assess employee caregiver need**
- Respond with Caregiver and Respite Seminar**
- Respond with Support Group**
- Respond with Counseling Referrals**
- Respond with Respite Referrals**

**Businesses: join local and state-wide coalitions!**

# *Ex: Creating Community Awareness and Dialogue Spaces*

## **Community Event: An Art Installation**

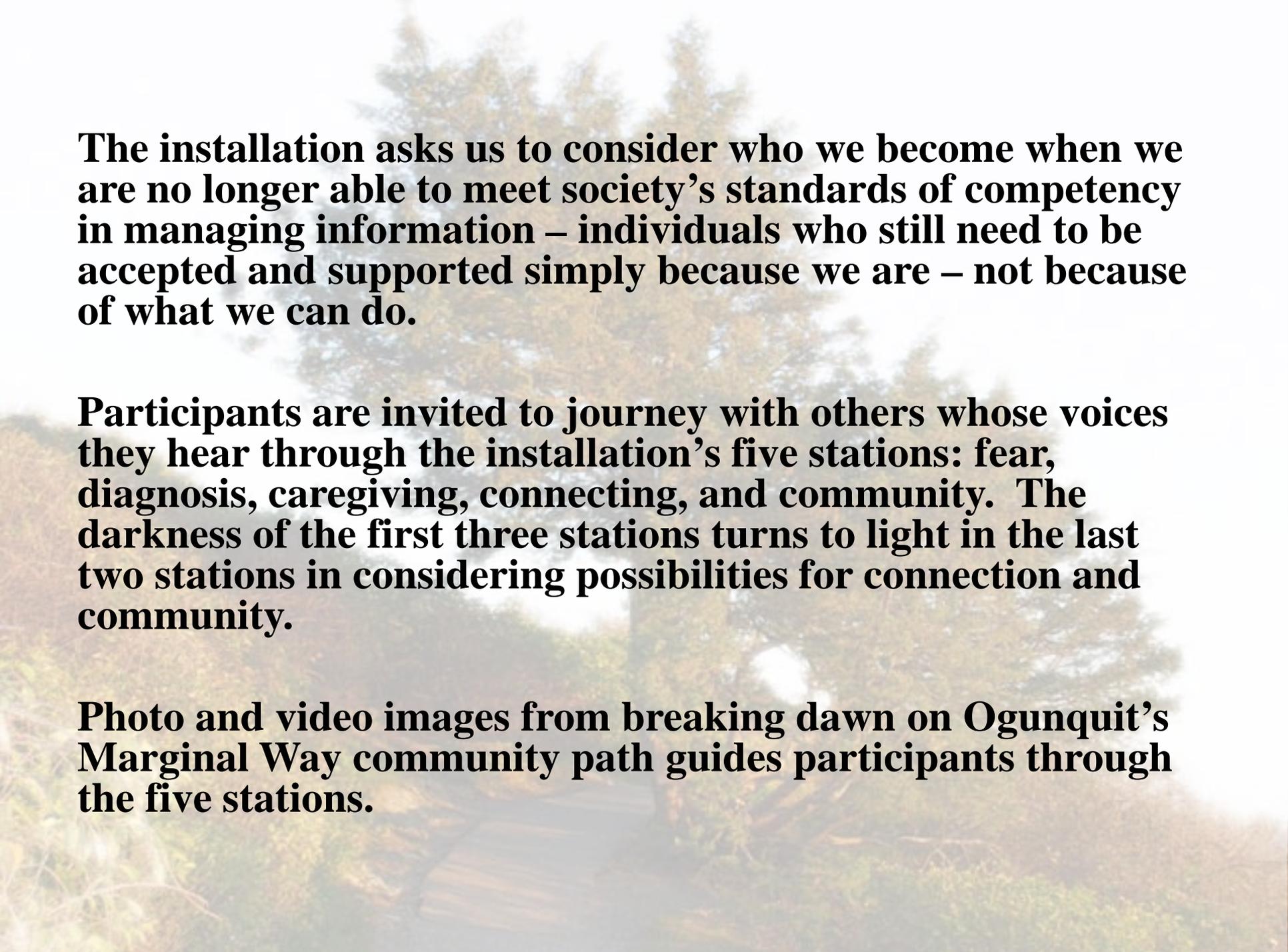
- ***Process:*** grant, advisory group, interviews, editing of multi-media, implementation, evaluation
- ***Outcomes:***
  - opened a space for dialogue about the inner workings of caregiving – its pain, its humor, its journey
  - Shifted caregiving from being an invisible, personal journey to a visible, public journey that, when shared, connected others and invited them to consider caregiving and respite needs

## ***Dementia's Way: A Meditation on Presence and Connection***

***Dementia's Way* is a multi-media installation that seeks to provide a community space to collectively consider the redemptive and grace-filled aspects of memory loss and dementia.**

**Participants visit five stations where voices from interviews mix with other texts including video, photos, and games and speak of grace, heartbreak, presence, and connection.**

***Dementia's Way* is an invitation to explore and honor pilgrimages made as we lose our minds – as we transition from identities based on managing data and information through recall and processing, to those based simply on presence.**



**The installation asks us to consider who we become when we are no longer able to meet society's standards of competency in managing information – individuals who still need to be accepted and supported simply because we are – not because of what we can do.**

**Participants are invited to journey with others whose voices they hear through the installation's five stations: fear, diagnosis, caregiving, connecting, and community. The darkness of the first three stations turns to light in the last two stations in considering possibilities for connection and community.**

**Photo and video images from breaking dawn on Ogunquit's Marginal Way community path guides participants through the five stations.**

### ***Station One: Fear's Haunting***

Participants are asked to join the voices they hear and speak their thoughts and fears aloud. These will become part of the music and soundscape, transformed from individual voices into music as they walk through the stations, culminating in an ever-changing community musical fabric in station five.

### ***Station Two: Memory's Diagnosis***

Participants are asked to take a card and, without looking at the date, try to find where it fits in the collective's memory timeline - as they listen to voices speak about memory loss and its implications.

### ***Station Three: Caregiving Inscription***

This shrine area honors all who journey with dementia and provides a space for considering how caregiving difficulties and blessings change those involved.

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### ***Station Four: Connection Possibility***

Participants are invited to consider possibilities for connection and presence including movement and music.

### ***Station Five: Community Inclusion***

The last station celebrates a place for everyone in community and nature. The fears expressed aloud earlier, in Station One, have been woven throughout the walk and culminate in this final community soundscape.

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# Interviews (sample questions & response)

## *Loved Ones*

**Do you know someone living with memory loss?**

**How does this affect their lives?**

**How does it affect yours?**

## *Connecting*

**How did you try to connect with them?**

**Tell of a time when were you felt you were able to connect.**

**Tell of a time when you could not.**

## *Impact*

**How are they changed by the journey with your loved one?**

**How are you?**

**How are we as a community?**

**What do we learn about dementia?**

**What do we learn about them?**

**What do we learn about ourselves?**

# **Together our respite coalitions can:**

- **Seize this historic opportunity to make caregiving and respite valuable beyond the human services and non profit sectors, to corporate America as well**
- **Define respite, brand it, make it accessible and desirable – a necessary response to caregiving needs that are visible and valued**
- **Create spaces in all our organizations and activities for caregiving and respite experience moving them from isolation and integrating them into all our sites including the arts, sports, shopping, leisure**
- **Create safety for caregivers to tell their stories to remind us of their value and the need for us to respond**
- **Grow partnerships with businesses who can use their CSR dollars and volunteers to support the respite movement**



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