

# Arts & Culture

## Designing a Life-Worth-Living Community



**John Zeisel PhD**

*Founder*

*The I'm Still Here Foundation &  
Hearthstone Alzheimer Care*



Hope

*In Healthcare & Design we each have  
a choice between*

Despair &  
Hope

# We Need to Change the Public Narrative of Alzheimer's

- **DESPAIR**

- **HOPE**

## **Facing the unknown & the ambiguous**

- We are afraid &
- We get angry
- & we look for the quick fix

- We are **curious** &
- We become **creative**
- & start a campaign for the slow fix



# The “Despair” Model

*A Self-Fulfilling Prophecy*

See the negative



# The “Hope” Model

*Embracing the Present*



*Hope =*

YCMAD

You Can Make a Difference

*As “Designers” in the  
broadest sense*

YCMAD

You Can Make a Difference

**Where do we find  
hope?**

**In our curious &  
hardwired brains**

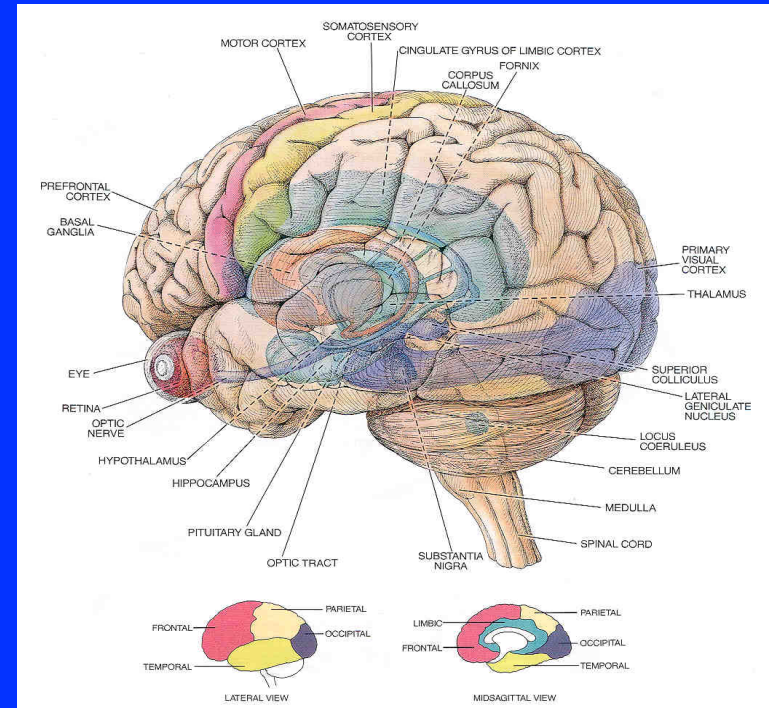
# Our brains are made to explore & discover

## We are naturally curious & creative

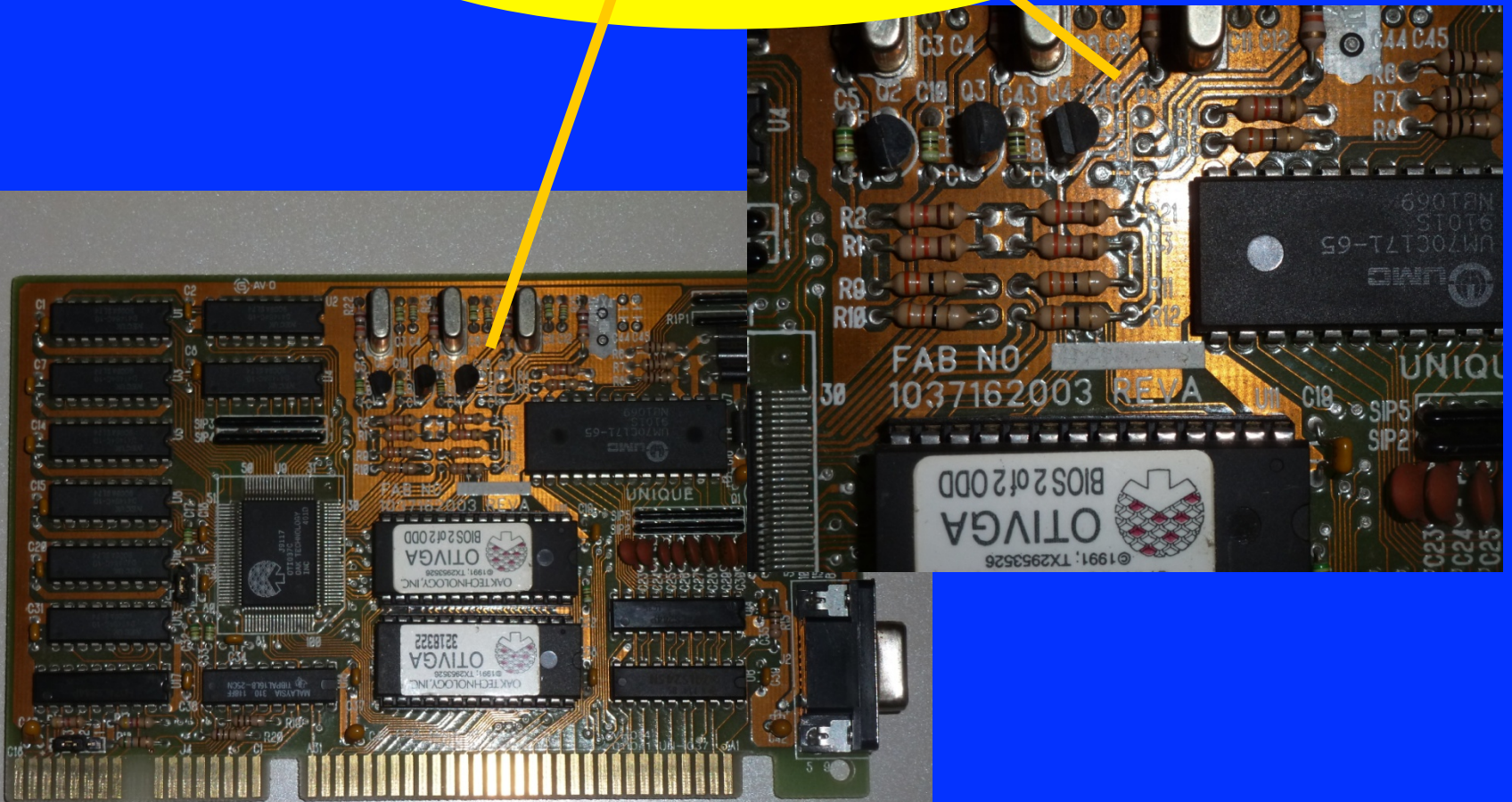
***The interpreter:***  
*Makes sense of the world*

***The actor(s):***  
*Perceives, senses, & acts on the world*

***The comparer:*** *Tests actions against experience*



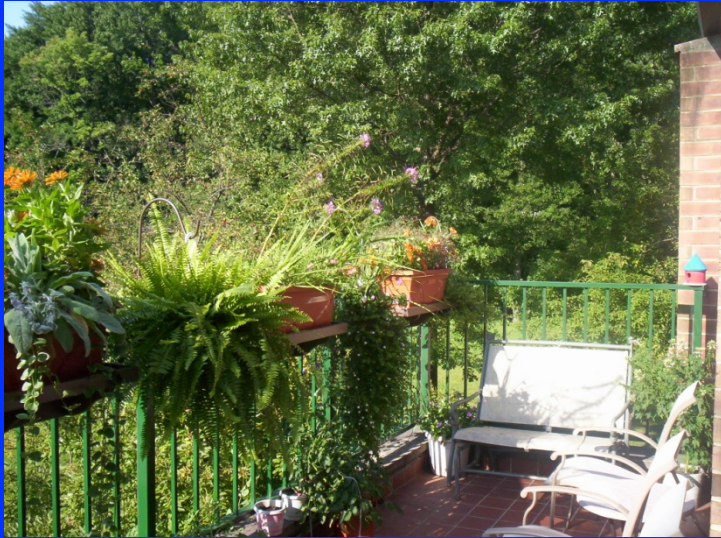
# Hard-wired



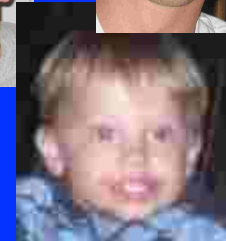
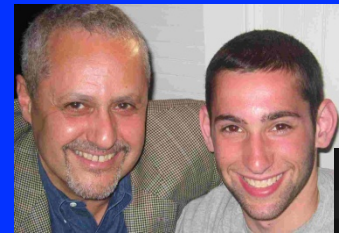


# Hard-wired, pre-set, universal,

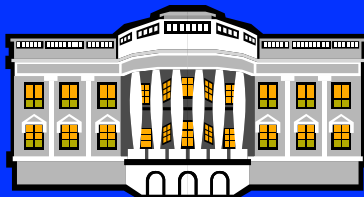
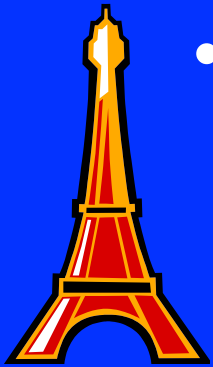
- Feelings about trees and greenery



- Smiles & frowns—all facial expressions & the archetypal stories that make us happy, sad, frightened, angry, & disgusted



- Using landmarks to find your way



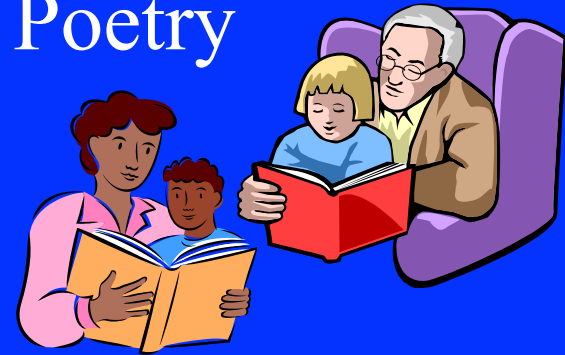


- Responses to a mother's touch



- & Creative and artistic expression of all sorts

Poetry



Visual expression



Dance



Music



# To be healthy our hearts, minds & bodies need:

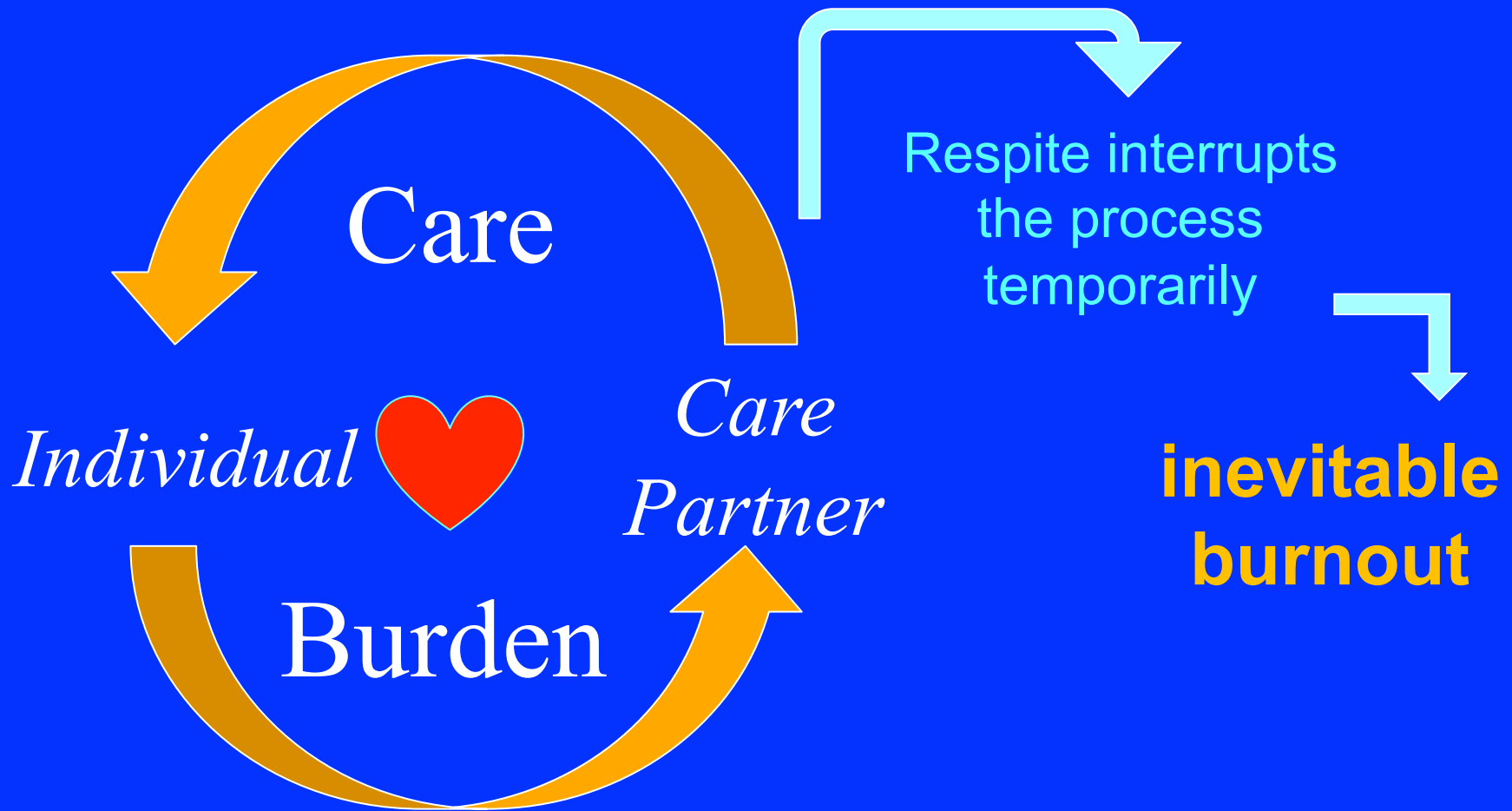


# A Hopeful Community Program

## It Takes a Village Program

- Guided Museum Visits, Meet Me @ the Movies, The Circus, Poetry, & every cultural venue a community has to offer from sports to museums to parks

# The Individual to Individual *Mutual Dependence Dilemma*



# The Community Dementia Problem

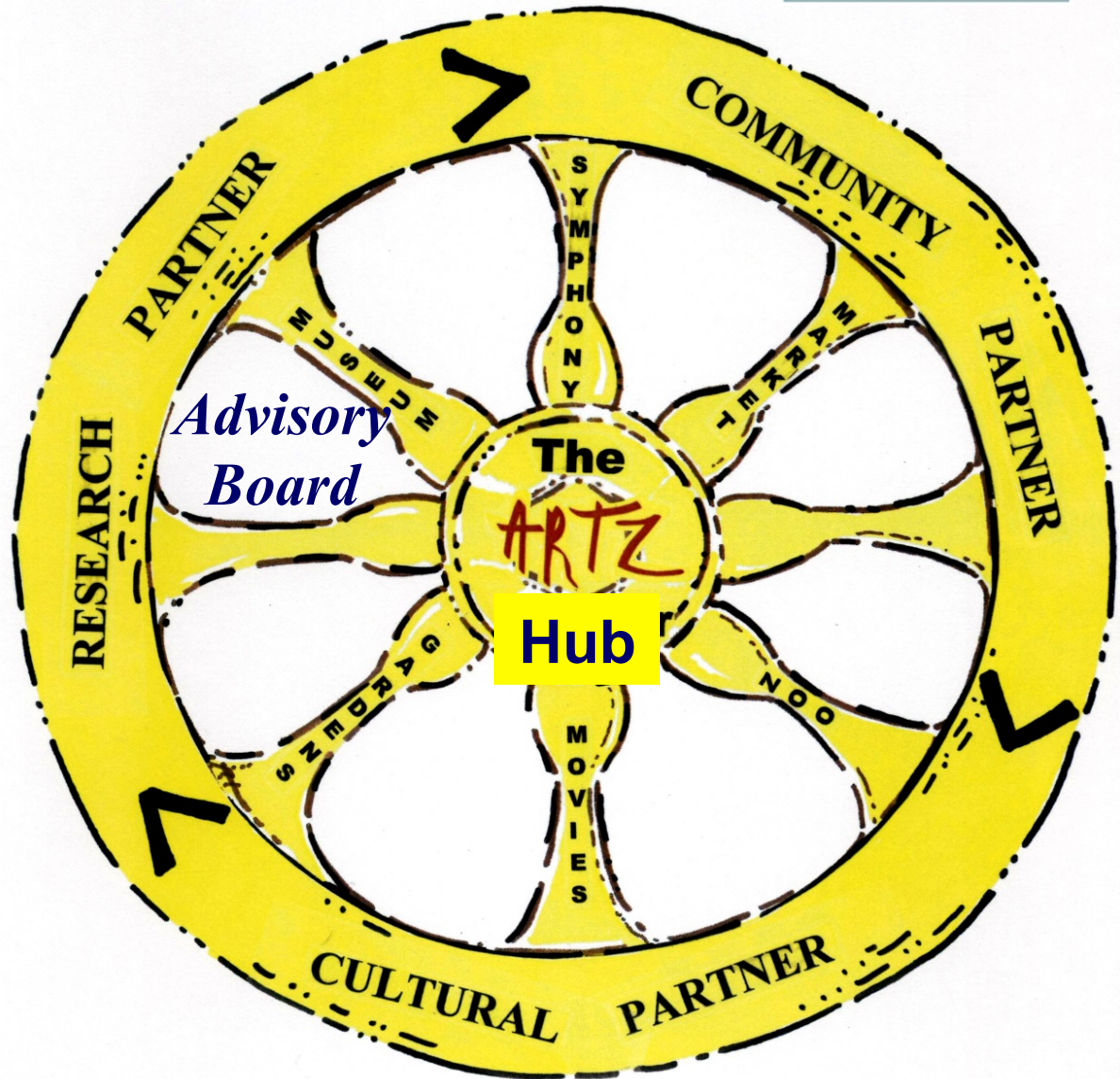
Fear

Stigma

Costs

Health care

A  
*Community  
Response:  
It Takes  
a Village  
hub, spokes  
& partners*



# The basis of the program

- People **learn procedurally**—and those with dementia maintain that
  - Every Week
  - Same day of week
  - Same time of day
- Being in Community is a human right
- Most public resources are underutilized
- Engagement in community cues appropriate behavior



# It Takes a Village Program Brookline, MA





# Larz Anderson Auto Museum



# Coolidge Corner Theatre



# Brookline Arts Center



# Brookline Senior Center



# Yoga in the Village



# Brookline Historical Society



# Panera Bread Café



## John F. Kennedy Birthplace



## Frederick Law Olmstead National Historical Site



## Brookline Booksmith



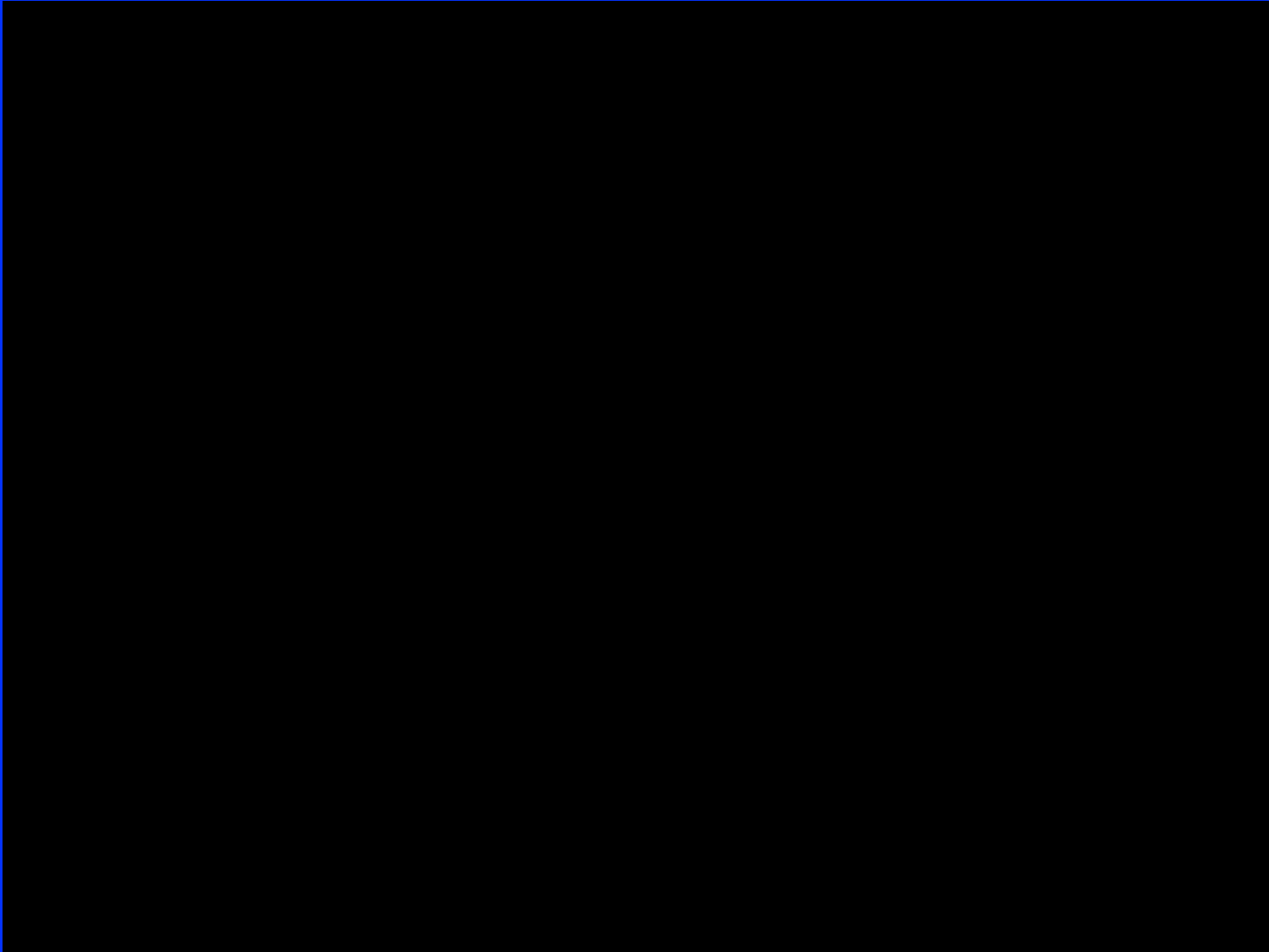
## Brookline Music School

# Inviting the community

## *The Threshold Problem*



# It Takes a Village @ JCHE



# The latest participant

- Greater Manchester Fire Service with 41 Fire Stations.
- A place to visit, enjoy, & learn
- Firemen (& woman) will learn about dementia (more than just becoming “dementia friends”)
- Meat on the bone for the Dementia Friends program
- Meat on the bone for the Dementia Friendly Communities program

**The Human Rights Issue:  
The UN Declaration of Human  
Rights: Article 1**

*“All human beings are  
born free & equal in  
dignity & rights.”*

# The Human Rights Ladder





For many the real conflict is between:

**Choice**

**Risk**

**Safety**

# Convention on the Rights of Persons with Disabilities (2013)

*requires the abolishment of*

- **Substitute Decision Making**—*In the name of safety*
  - DOLS—Deprivation of Liberty Statement
  - Guardianship & Trusteeship
  - Power of Attorney

## IN FAVOR OF

- **Supported Decision Making**
  - Ways to help people with dementia make informed choices to fulfill their human needs—visual vs. verbal for example

# And what are the choices we give up when we lose our rights?

- Sexual activity
- Getting up & going to bed
- Medications

## *AND ALSO*

- Joy
- Play
- Learning

# Some Village Examples

Evidence-Based  
Museum Visits

Excerpt

I Remember Better  
When I Paint

Eric Ellena & Berna Huebner



# Universal categories emerge for paintings, music & other art forms

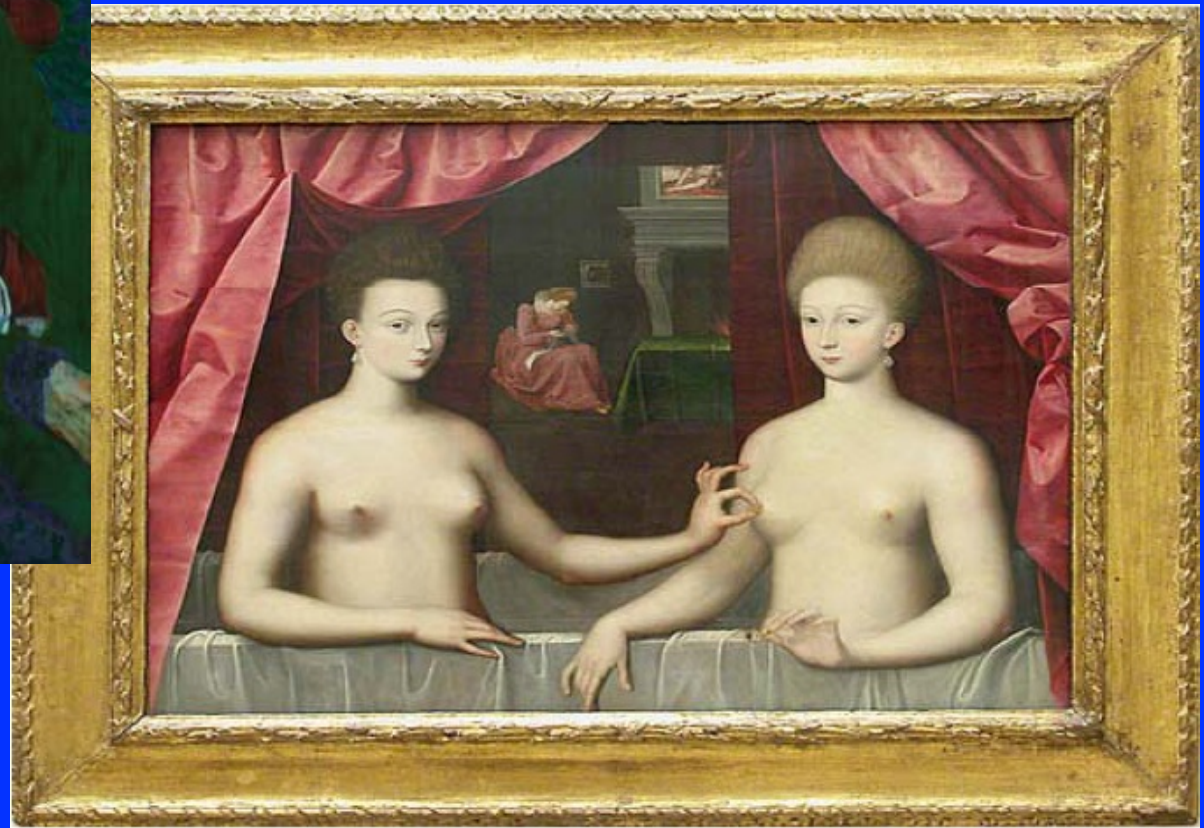
- Moral judgment
- Emotion
- Narrative
- Self-revelation
- Memory jogger
- Object identification



# Moral Judgment

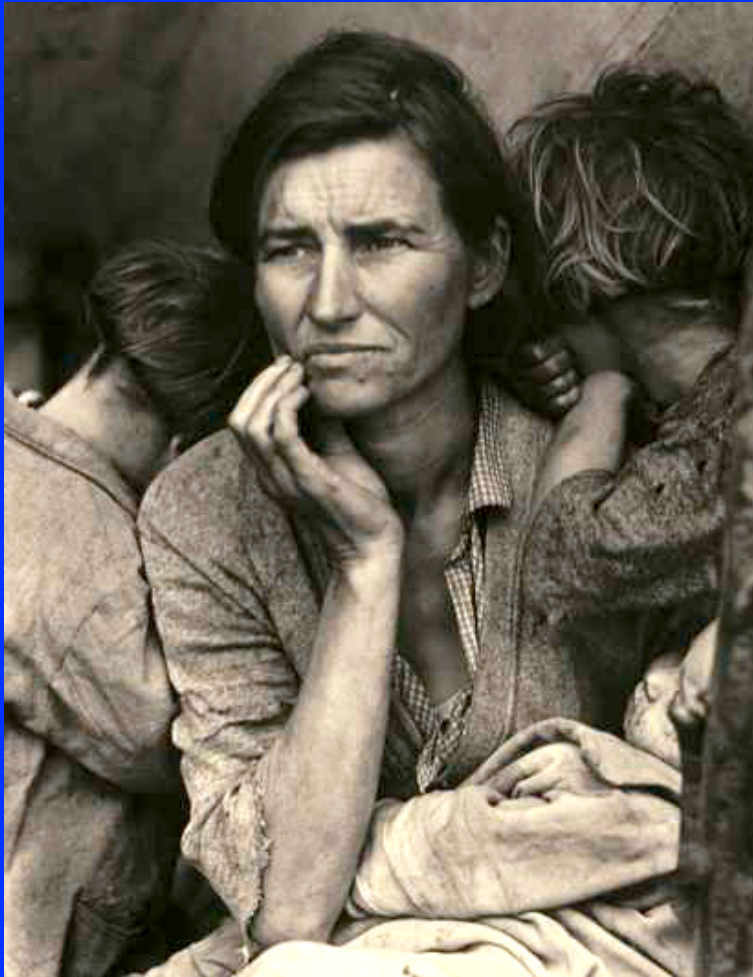


Henri Toulouse-Lautrec, *La Goulue at the Moulin Rouge*





# Emotion



# Narratives evoke focus of attention

## The favorite narrative painting at MoMA



Andrew Wyeth. (American, born 1917). *Christina's World*. 1948. Tempera on gessoed panel, 32 1/4 x 47 3/4" Purchase

Meet Me at the  
Movies



# Meet Me at the Movies

## A Walk Down Memory Lane

A Film Program for People with Alzheimer's Disease

Wednesday, June 20, 2007

2:00 - 4:00 pm

Tribeca Cinemas  
54 Varick Street  
New York, NY

**Volunteers and Supporters Needed!**

'A Walk Down Memory Lane' is a one-of-a-kind film experience, designed specifically for people living with Alzheimer's disease and their loved ones, utilizing iconic film clips from the 20th Century.

This program will demonstrate how film can be a form of treatment for people with Alzheimer's disease. Film has the power to connect us with our deep-rooted emotional memory—the type of memory that never goes away.





## **Meet Me at the Coolidge...and Make Memories™**

An interactive program for people living with memory loss that utilizes classic film clips to bring about increased feelings of self-esteem and social inclusion

A collaboration between

ARTZ: Artists for Alzheimer's®

&

The Coolidge Corner Theatre Foundation



# A day at the Big Apple Circus





Copyright 2006

# Would you like to participate? Everyone says “yes”

- Why don't we?
- Because it is more difficult to cross the threshold with persons with dementia than any of us acknowledge.

# The Threshold Problem

- *Perceptual Barriers*

- Inertia
- Perceived difficulties
- Stigmatized attitudes
- Belief that persons with dementia do not benefit from such things
- Extreme risk-averse attitudes

- *Practical Barriers*

- Lack of transportation
- Not enough staff
- Difficulty getting residents ready
- Potential risks
- Participant safety
- Lack of knowledge that such events are available



# *A Poetry Jam*

**BOWERY POETRY CLUB & CAFÉ**

308

**Smoothie Cafe**

OPEN 8am - Midnight

EVERYTHING  
IS SUBJECT  
TO CHANGE

BOWERY POETRY CLUB

SERVING THE WORLD POETRY

LIVE'S  
LUCKY'S  
CAFÉ

Where vegans and vegetarians meet

Lucky's  
COFFEE  
SMOOTHIES

PLEASE  
USE OTHER  
DOORS

# Alzheimer's Poetry Day

Bowery Poetry Club in NYC outlet for self-expression







Before



Boris “knows” who he is  
We all should be Boris the poet



After

Thank you  
*John Zeisel*

[www.ImStillHere.org](http://www.ImStillHere.org)

[www.TheHearth.org](http://www.TheHearth.org)

Twitter: @johnzeisel









# How complicated it is!

- Help everyone realize how much we all would lose if we had this attitude towards everything we do.
- Allow family members and residents to be involved in deciding whether the risks of community outings outweigh benefits.
- Train and retrain staff on how to safely bring residents into the community.
- Carry out training in the community on how to interact with persons with dementia.

# Pre-Planning

- Make sure everyone realizes that it's not just about the museums, musicians, or movies, but more **about the trip as a whole.**
- Leave a note the night before (in a communication log) so your morning staff is aware who you plan on taking Arrange a proper vehicle
- Make sure that all facilitators know when to step back and just observe, but know when to step in to allow for interactive engagement. The goal of many events is the discussion itself.
- 
- **Be flexible and plan for disruptions. Give yourself 30 minutes leeway in case anything comes up.** Things can happen that are out of your control, like the weather or participants not feeling well the day of the trip
-

- Have a contingency plan if the weather does not agree with your plans
- Make sure the organizer and driver **are comfortable** with going out.
- **Know your limits!** Do not take too many residents just because you have space. Rather take the right number to allow for that group to get the most out of it
- Meet with and educate the people you will be interacting with to give them tips about their interaction.
  - Most of all be sure to educate them that you all are there to have fun and do not want to be treated as if your folks are sick.

# Timing

- Consider the prep time of getting into the vehicle, traffic, distance from the best drop off location to the front door venue and then even from the door of the venue to the seat or meeting point.
- Look at timing implications of: Is the walkway/ pavement smooth for walkers, are you walking on grass, are there stairs, is there a ramp, are there refreshments if needed.

- Getting to and from the location: Take a trip to the place beforehand to get an understanding of the layout
- Make note of where the transportation vehicle will drop off participants and pick them up
- Make certain that the *lunch* to go includes appropriate diets for the each residents going, i.e. if someone requires a softer diet or is diabetic.
- Know if there are bathrooms, are they handicapped accessible and not down or up a flight of stairs, and where they are located.
- To maintain participant dignity bring a none-see-through professional type bag of incontinent supplies, NOT a plastic see-through bag.

- Role-call all by name, not by number, multiple times throughout the trip—essential for a safe outing. Counting heads is not accurate enough to prevent elopements.
- Give the job of calling role by name to person you trust the most, if it is not yourself.
- Make sure all staff and volunteers and family members who have cell phones with them, (and that are silent during any production) turn them on after the production and make sure they all have exchanged phone numbers beforehand.
- Make getting out in the community for an event the highlight of the day—something to look forward to. This will ensure that the focus and energy level for all who will be joining will be only about having a good time.



- Create events that give back to the community. When residents themselves create the giving event it is a way for everyone to make a difference.
- Every outing is about the meaning behind, not about how many people you can take.
- The trip is only over when all your participants are back in their home safe and smiling! Enjoy the moment!
- Again, the trip as a whole is what it's all about. From the moment you leave the building, till the moment you return home.

# Inquire Beforehand

- Where exactly is the best place or handicapped accessible entrance, and
- Will there be someone there to help/welcome us when we arrive.
- Are there bathrooms along the way?
- Are there chairs or benches while you are waiting?
- Are there coat checks, storage areas for wheelchairs / walkers / canes for your specific group

Thank you

*John Zeisel*

[www.TheHearth.org](http://www.TheHearth.org)

[www.ArtistsForAlzheimers.org](http://www.ArtistsForAlzheimers.org)

