

2009 Next Steps Think Thank: How Can We Radically Transform Activities in Long Term Care?



UWM Center on Age & Community
Prepared by Amy Wickland and Anne Basting

About this White Paper...



My hope for this Think Tank was to bring together leaders in both worlds – that of ART, and that of AGING

- Anne Basting

You are reading the White Paper from UWM’s Center on Age & Community’s 2009 Next Step Think Tank. Our Think Tank series is designed to do just what it says...gather a group of people together to think (in a room actually), about what the “next steps” might be to push the thought boundaries of a given area in order to improve the experience of aging. This is our fourth such Think Tank, supported by generous funding from the Helen Bader Foundation.

The idea for this Think Tank emerged from a sense of frustration I’ve had from over 15 years of working at the crossroads of the arts and aging. There is so much exciting work happening in the arts. Incredible, large-scale projects that empower a given community through rigorously designed and implemented art-making. Paul Chan staged *Waiting for Godot* on a New Orleans street corner to huge and art-hungry audiences. Harrel Fletcher and Miranda July created *Learning to Love You More*, a website with compelling “homework” assignments (in the performance art tradition) that visitors to the site could try at home and mail in to share.

In the field of aging, the arts have had a small but steady following. Yet the vast majority of art projects in long term care, seemed content to stay within a general therapeutic framework and within the walls of a facility.

My hope for this Think Tank was to bring together leaders in both worlds – that of ART, and that of AGING – so see whether guided conversations and some deep thinking might ignite change in the way we conceptualize “Activities” in long term care.

Our framing questions were? “How Might We Radically Transform Activities in Long Term Care?” How might the conceptual and community-building work in the arts benefit the world of aging? How might the practical knowledge of those in aging inform the ideas of artists? What do caregivers and older adults themselves have to tell us about “activities”?

We invited cutting edge, emerging artists like Nic Tobier (www.everydayplaces.com), Stuart Hyatt (www.teamrecords.org), and Steve Lambert (www.visitsteve.com). We invited leaders in the field of



aging services, people who could return and really make change, like Jed Johnson of EasterSeals, Kathy Kelly of the Family Caregiving Alliance, and Debra Cloud of the American Association of Homes and Services for the Aging.

We invited artists who are also arts educators, like Michelle Lopez Rios and Kim Cosier, who could help us think about how to translate our ideas to the next generation. We invited caregivers and older people, who could hold our collective feet to the floor.

We also invited deep thinkers about the role of the arts in culture at large, like Arlene Goldbard, and shapers of culture like PBS's Judy Diaz, and web designer Ellis Neder. All of those we invited were enormously generous with their time and ideas.

We began on Wednesday May 13th with something I consider to be a model project. CAC's 2008 artist in residence David Greenberger and the Paul Cebal Stage Ensemble (*pictured*) played a concert at Milwaukee's gorgeous Pabst Theater, a concert built of the 38 songs Greenberger and Cebal created and recorded from Greenberger's interviews with 60 people with memory loss in Milwaukee. The show truly set the tone for the two-day endeavor. This was big thinking, big art, big feeling, and potentially big change. This was what we were talking about.

This white paper chronicles the two days of conversations that followed the concert. On the first day, the Think Tankers met at Luther Manor, a continuing care facility in Milwaukee. If we were going to radically transform activities in long term care, we reasoned, we all needed to know what long term care looked like. We alternated between small and large group conversations and projects. After 8 hours together, we gave folks the evening off, asking them only to prepare synopses of their small group's ideas to present the next day at our Public Forum.

The following morning we opened the conversation to 40 more people from the greater Milwaukee area and formed blended small groups of new folks and Think Tankers to help challenge and further our thinking from the day before. In hindsight, I see several results of the Think Tank overall:

1. We began complex discussions that can continue. In some ways, I see the warm conversations and questions we raised, as our greatest accomplishments.
2. We identified core conceptual problems with the way Americans view older adults, and married those conceptual challenges to projects (what we used to call activities...) through which we (artists, older adults, and intergenerational teams) could work together to bring about change.
3. We fought to bring "meaning" to projects by linking them to purpose and community (both small and large), and created a model to describe how such projects might look.
4. We created outlines for several projects...some of which I can barely resist diving in to do right away!

You will likely find more themes and compelling points in these pages. I invite you to visit our website (www.aging.uwm.edu) and email us your thoughts to keep the conversation going.

Enjoy!

Opening Remarks: Anne Basting



Welcome to the 2009 Next Step Think Tank: Radically Transforming Activities in Long Term Care - in 48 hours or less... We're trying to do something that might be either impossible at the most, or frustrating at the least. Thank you for coming along for the ride – and for risking that frustration. We also might come up with some gems that reach a broad audience. It's going to be hard...but I think it'll be worth it.

I've been incredibly lucky. There really is no "field" of arts/humanities/aging studies. Aging centers usually are run by scientists who get big grants that feed the university. With an arts person at the helm here at Center on Age & Community (CAC), UWM knows that the National Endowment of the Arts (NEA) doesn't offer 47% indirect return to the campus. So, I get to do things here that other aging centers can't do.

I also have the Helen Bader Foundation to thank for that. They steadfastly believe in the arts, and I'm forever grateful. They are partial sponsors of our artist residency program (with the Brookdale Foundation), and they sponsor our Next Step Think Tank series. They allow us to be visionaries – and they are visionaries themselves.

I want to mention a couple of people who, unfortunately, can't be here with us today:

Raoul Deal – incredible teacher and visual/performance artist who is swamped under with grading and a family health emergency.

Rocille and Roger McConnell – Roger took a fall and is recuperating, and Rocille, his wife, will join us tomorrow.

Jed Levine – who is the Vice President of the NYC Chapter of the Alzheimer's Association, and one of those people who has always understood the value of the arts to older adults.

Robin Mello – a storyteller and coordinator of UWM's K-12 Theatre program, who had to travel out of town unexpectedly.

Susan Perlstein – Founder of Elders Share the Arts and the National Center for Creative Aging, who is with her brother in hospice in Arizona.

Think Tank Participants



Terri Bartlett, *Activity Director, Luther Manor Health Care Center, Milwaukee, WI*

Deb Bera, *President of WRAP, Vice President, National Association of Activity Professionals, Stevens Point, WI*



Carmen Bowman, *Owner, Edu-Catering: Catering Education for Compliance & Culture Change, Denver, CO*



Deborah Cloud, *Vice President & Senior Editor, American Association of Homes & Services for the Aging, Washington, DC*



Kimberly Cosier, *Area Head, Arts Education, University of Wisconsin-Milwaukee, Milwaukee, WI*



Judy Diaz, *Managing Director of audience and brand strategy at PBS and PBS KIDS, Alexandria, VA*



Rose Marie Fagan, *Co-Founder and Founding Executive Director, Pioneer Network, Rochester, NY*



Arlene Goldbard, *writer, speaker and consultant, Berkeley, CA*

Today's Ground Rules

1. More people than ever are aging. More people than ever have cognitive disabilities with age. Yet it's not about THEM – it's about US. Talk about older people as though you're talking about yourself. Talk about activities/projects as though you're designing them for yourself.
2. I'm hoping to move us beyond silos, territories, turf, and boxes.
 - a. We are an incredibly diverse group in regards to experience with aging. That is by design and to our advantage.
 - b. Call out "huh?" if someone uses a term you don't know. Letters after your name don't matter here. Your ideas, built on your experiences, do.
3. People age everywhere. Let's talk about reaching people where they live. Alone or in groups. This will be hard. But try to remember that most older people do not live in group-care settings.
4. There is little continuity in aging services. We serve people in one setting, and then a whole other group serves them in another setting. Different rules, different codes etc. Let's try to imagine transforming activities for people wherever they live – and how this approach might follow them from one setting to another.

Here is what I hope we come away with today:

1. Describing the problem (s) in our own terms, from our own experiences.
2. Meaningful projects to do with people with dementia (as the "normal" group), and older people in general.
3. A definition of "Meaningful"
4. Identify 10 specific reasons why we aren't doing what's right
5. Identify 10 specific ways to change those 10 specific reasons.
6. Identify (if we haven't already) additional resources to enlist in helping the cause.
7. Identify the questions that still haunt us – what we need to push ourselves on tomorrow in the Public Forum

Finally, a big thank you to David Keller, CEO of Luther Manor, for being such a generous host today.



Gay Powell Hanna,
*Executive Director,
National Center for
Creative Aging,
Washington, DC*



Amy Horst,
*Head of Community Arts
Department, John Michael
Kohler Arts Center,
Sheboygan, WI*



Stuart Hyatt, *Senior
Project Designer, M12,
Founder of TEAM Records,
Indianapolis, IN*



Jed D. Johnson,
*Assistant Vice President,
Older Adult services;
Director, National Center
on Senior Transportation,
Washington, DC*



Kathleen Kelly,
*Executive Director, Family
Caregiver Alliance, San
Francisco, CA*



Steve Lambert,
*Senior Fellow, Eyebeam
Center of Art and
Technology, Brooklyn, NY*



Brad Lichtenstein,
*Producer and President,
371 Productions,
Milwaukee, WI*



Michelle Lopez-Rios,
*Assistant Professor, Dept.
of Theatre, University of
Wisconsin–Milwaukee,
Milwaukee, WI*

Questions In Advance

Before the Think Tank began, the participants were invited to ask questions probing what was wrong and what was right about activities in long term care; also how activities may be transformed. Below is a sampling of the questions they posed to each other.

- What kinds of activities can be used to bridge differences in abilities?
- How can activities be meaningful for the individual and not “one size fits all”?
- Can we eliminate the word “activities” in long term care? Why not use a language that emphasizes using tools for engagement or methods to interact in meaningful ways?
- How can the residential setting be a meaningful part of the greater outside community?
- How would you feel about participating in a given activity if the roles were reversed? - If you were the client?
- Why do we continue to “culturize” older adults into childish and herd-like activities?
- How can we transform activities to encompass the baby boomers needs as they start to utilize long term care services?
- Why do we accept the responses (excuses) like, “The people in my group home, (adult day center, nursing home) love to play bingo and would have a fit if you ‘took it away.’” Or “They [older adults] want to decorate the room in paper hearts for Valentines Day and always ask why we aren’t doing that any more...”
- What would make activities seamless, a natural part of living and integrated, versus set apart from living and scheduled in silos?
- How can activities help people in long-term care be seen as whole people who are engaged directly with all the aspects of their characters, even deeper emotions and desires; and engaged with the world outside of care, in real time, rather than seen through the rear-view mirror of life?
- I think of art as sacred play; so, not every activity must be purposeful in a practical sense, but can some sense of purpose be infused into activities?
- How much do we really know and understand about residents’ lives and life patterns before we put them in programs?



Cassandra McShepard,
Caregiver and Host of AM 1290's, "That's What I'm Talking About", Spokesperson for the Wisconsin Alzheimer's Institute, Milwaukee, WI



Beth Meyer Arnold,
Director, Luther Manor Adult Day Services, Board President, National Adult Day Services Assoc., Milwaukee, WI



Ellis Neder,
Founder, Sway Design, Brooklyn, NY



Sharon Nichols, *Clinical Specialist and Regional Consultant, Genesis Health Care Corporation, Portsmouth, NH*



Will Reichardt,
Caregiver, Linden Grove Health Care Center, high school student, Waukesha South., Waukesha, WI



Stephanie Sue Stein,
Director, Milwaukee County Department on Aging, Milwaukee, WI



Nick Tobier, *Artist and Educator, School of Art and Design, University of Michigan, Ann Arbor, MI*



Maureen Towey,
Artist, Sojourn Theatre, Brooklyn, NY



Kate Waldo,
Culture Change Specialist, PHI, Manchester, NH

Questions When We Arrived

On the day of the Think Tank, Basting began the discussion by asking the participants for their questions. After reading over the materials that were sent to them, listening to the initial round of questions, and attending the concert Wednesday night, what questions did they wish to have answered over the next two days?

- People know that there's a better way of doing things, but there is no real sense of urgency: Why should we change if things are working OK, now? How do we create this sense of urgency?
- Should it be about engagement or activity programming?
- How can we emphasize quality of life vs. cost?
- How do you make change sustainable?
- How do people want to live? What do they want to do?
- How do you change the dialogue around elders' lives, to stop pathologizing the things that happen at the end of life? How do we change the way we view end of life issues?
- How do we promote the concept/value of "active aging" – taking it out of the frame of loss? Aging is not a dying process, but an active process. There is still a lot of life.
- How do we get motivated to age well? To have a quality of life not in some distant future, but every single day?
- How do we recruit different groups to help solve this problem?
- How can we differentiate activities to meet the various levels of abilities among the older adults so each person can match his or her highest potential?
- How do you share results in a way that allows people in different organizations to see what is going on?
- How can we recognize that even the smallest responses, such as a smile, can have astronomical value?
- How do we present the magnitude of the joy of the moment of engagement?
- We could sit in this room and say yes we value that; but in the regulatory arena, are we able to communicate the value of things that do not necessarily have a noticeable end-value?
- People are familiar with teaching children (pedagogy) but not teaching older adult learners ("gerogogy" or "androgogy"). How do we get people to acknowledge the difference between working with older and younger people?



"What are best practices? Amazing success stories that people are familiar with? How have other countries handled this? Not only now in the US, but different cultures and countries throughout time."

– Steve Lambert



What's Wrong with Activities In Long Term Care?

After the participants had a chance to brainstorm questions, small groups were asked to discuss what was wrong with activities in long term care (LTC). Why exactly do we need to radically transform activities in long term care? Here are their responses:

Society's View of Aging is Wrong

- There is a lack of value of aging and disabilities.
- There is a lack of value of our elders.
- Aging isn't one size fits all, but is very diverse among different groups.

Lack of Agency

- There is an emphasis on planning and entertaining, rather than orienting toward what people want, which is engaging rather than just entertaining.
- We must educate people on the outside of LTC about what their expectations can and should be.

Capitalist System

- *"So many times profitability is the issue. We are accountable to so many agencies. What kind of frame do we need to put this in to be able to focus on the person?"*
 - Beth Meyer Arnold.

Branding and Stereotypes of the Elder Population

- Elders are seen as non-persons when they stop producing for society and as becoming more dependent.
- People are defined by age, not individuality.
- The focus is more on the younger population.
- There is a gap in the media representation of older adults and the younger generations.
- We need the help of the younger generations to make changes.

The Problem of Discussing What Should Take Place at the End of Life

- There is not enough attention paid to the conscious creation of community that connects people to life.
- Culturally, there is less social interest in the well-being of older adults than there is with kids.

What's Right with Activities in Long Term Care?

After a discussion of what was wrong with activities in long term care and possible sources of the problems, the group shifted to discuss what was right –what kind of change are we envisioning?

- Activities should celebrate individual expression.
- Activities should have a greater social consciousness, a connection to a larger group. They should be part of something bigger.
- Activities should be purposeful.
- Activities should provide pleasure.

Arlene Goldbard wrote down her own thoughts regarding issues in the Think Tank after the first day was over. Here are just a few:



“Transforming activities is an encompassing process, involving every dimension from individual awareness to a global transformation of understanding and action.”

“Instead of treating public issues like private troubles, what’s needed are interventions at every level, to relieve the burden on families and reframe aging as a universal human process, not a medical problem.”

What is the Meaning of Meaning?

Basting asked the group to consider that makes projects meaningful to us. We infused this discussion into the “enchantment” activity. Here are some quotations that we handed out to the group to inform their discussions of meaningfulness:

From “Creativity, Independence and Meaning” (Easter Seals Training Modules and Activities for Centers Serving Older Adults)

- “Effective activities are: meaningful, purposeful, include individual choice, renew interest in life, and bring pleasure.”
- “Meaningful activities are personally or culturally valuable and important to the individual.”
- “Purposeful activities have a goal that can be achieved, even if it is pleasure or entertainment.”
- “Purposeful and meaningful activities build relationships, skills, and meet core psychological needs.”

“Having a sense of direction, a sense of order, and a reason for existence, a clear sense of personal identity, and a greater social consciousness”

- Gary Reker

“We get a sense of meaning in our lives ‘by creating a work or doing a deed,’ ‘by experiencing something or encountering someone,’ and ‘by the attitude we take toward unavoidable suffering.’”

- Victor Frankl

“Meaningful occupations are conceptualized in occupational science literature as ones ‘which enhance individual well-being, help establish and maintain identity, and help connect ones’ past, present, and future into a meaningful life.”

(Ikiugu, 2005, 21)

“A series of studies show that decreased mortality and psychological disability occur when individuals feel a sense of usefulness, purpose, and meaningfulness.”

(Ikiugu, 2005, 22)

Enchanting Activities



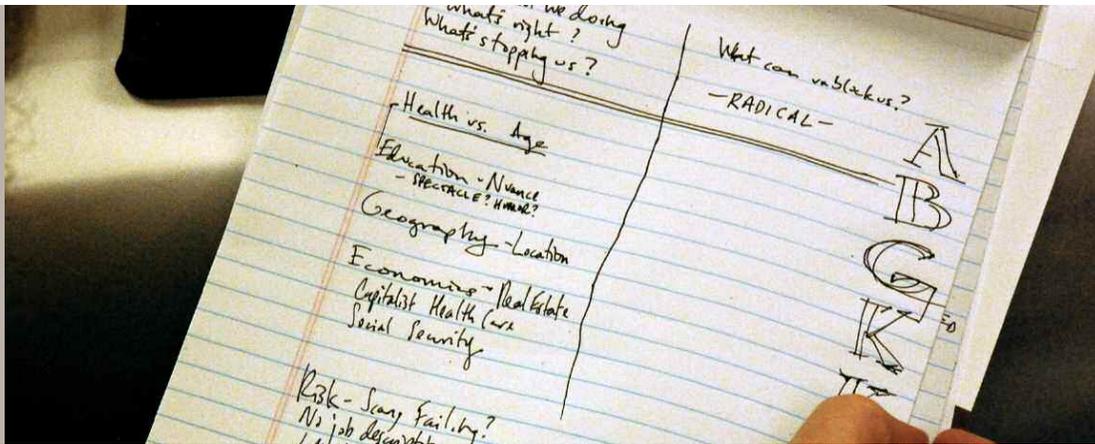
"Where the rubber meets the road, everyone has the capacity to transform activities for those in need of long-term care or in structured environments, by "enchanted" even mundane tasks and simple play through creativity, remaining present and responsive to the whole person, rather than treating an individual like the embodiment of his or her deficits."

- Arlene Goldbard

Basting challenged the four small groups to "enchant" several activities from a list of 101 activities recommended for people with Alzheimer's disease (see alz.org). Basting defined "enchantment" as making something meaningful by adding a layer of mystery and wonder. The purpose of this section of the Think Tank was to challenge the way we think about "activities" on a very practical level. A list of ten activities (of the 101) was given to each small group to brainstorm, and groups dispersed throughout the Luther Manor (LM) campus (guided by a LM activity staff member) to be creative in the context of long term care. After forty minutes, the groups returned to share their ideas.

Activity: "Sorting Silverware"

The idea of being "fake" (sorting silverware disconnected from an actual meal or purpose) could be removed and a layer of meaning could be added by having the silverware be put away from an actual event. This activity would then provide two points of contact. There is a role for quiet people in the midst of what seems like chaotic social times. Sorting silverware also provides shared time between residents, staff, and volunteers in which one another's work and time is validated. During the act of putting away the silverware, they could discuss the event and the meal they shared, as well as meals they shared at other times in their lives. The participants could create their own invitations to an actual event by cutting out pictures from magazines and making a collage of images around the theme for the meal. Merging these activities, (creating invitations and a collage of the event), gives a chance for individual preferences and abilities to engage collaboratively and build something larger together.



Activity: “Listening to Music”

The group “enchanted” the activity by adding dance to listening to music and renaming the activity with a more attractive name, such as “Bust a Move!” Other ideas included:

- Include younger generations in this activity by having the older adults add different elements to the music and present them to members of the younger generation.
- Include people with disabilities and personal expression by having each participant activate the music by either touching the screen or using his or her own ideas.
- Use music with the TimeSlips storytelling method (www.timeslips.org) instead of pictures. Language-limited individuals could participate using only sounds or word fragments.

Activity: “Clipping Coupons”

A group at a long term care facility could clip coupons, talk about their experiences with similar products, then go to the grocery store and tape the coupons to the corresponding products for other shoppers to use. It might also be possible to write down short stories about the products from the participants and tape them to the products along with the coupons. This makes the activity meaningful by sharing personal experience, going on an adventure (to the grocery store), and being generative (giving the gift of story and savings). This activity idea was based on an actual activity done at Luther Manor.

Activity: “Stringing Beads”

This activity could be “enchanted” if bead color and shape became symbols of personal feelings to individuals who could not express their feelings. The beads could become a new language for the individual to communicate.

Activity: “Make Homemade Lemonade”

The lemonade could be turned into a business, like Jones’ Soda or Neumann’s Own. A label could be pasted onto the bottle with a story of the creators. A fact or statement could be included to facilitate a large-scale, public conversation.

Activity: “Baking Cookies”

Each participant would have a voice in selecting the type of cookies they wanted-either a favorite type or a family recipe. Everyone would have a part in making the cookies, from stirring the batter to licking the spoon. The cookies they make could be for a group of children from a local school. The children could come with stories about their favorite cookies and share them with the older adults. The children could also help to bake their favorite cookies with the older adults. This could be envisioned as a recipe, story, and cookie exchange. Also, perhaps, approach a local business about supplying the materials for the food preparation.

Activity: “Folding Clothes”

Don't just fold clothes, but make a game out of it, such as match a sock with its mate. Mindfulness could also be practiced by cleaning off the surface of the workplace as in the Japanese ritual of Osoji. Also, time should be taken for the activity to really be “in the moment.” One example given was folding a sheet. The participants get closer and closer to each other until they come together and meet in an embrace.

Activity: “String Up Cheerios for Birds”

Learn more about the birds; draw the birds; name the birds; and prepare the food as a gift for the birds.

Activity: “Scrapbooking”

Have the participant draw a picture of a favorite day and use it as a tool for storytelling.

What About Activities for the In-Home Caregiver?

The discussion turned from group settings to people living at home and other situations of one-on-one care. The group suggested that in these settings, one must come back to the individual and what they are interested in. Rather than concentrating on activities, the focus should be on creating a checklist for caregivers to understand and prepare for meaningful engagement.

Individuals could have a toolkit that helps frame the shared experience, including notions of developing a relationship with the person, being flexible, sharing success (failure free), allowing the individual to experience pleasure or joy, asking open-ended questions, thinking about social connotations beyond the actual person, intergenerational connections, neighborhood or community centers.

There should also be a shift in thinking for the home caregiver. Activities such as walking could be engaging by having a question in mind as you walk together. Another idea was to take along a camera and make a game of taking pictures of everything red (or yellow, etc.).

Why Aren't We Doing What Is Right?

The participants broke into groups to identify what was holding back facilities and caregivers from “radically transforming activities” when we seem to know fairly clearly what it is we are striving to achieve. Each participant drew from his or her own experiences in identifying why activities are not being transformed.

Fear of Change

- *“We are not afraid to fail in old, familiar ways, but we are afraid to fail in new ways.”*
–Arlene Goldbard.
- People think: “If the system works, why change it?”
- It’s risky to change things.

Money and Time

- Leaders need to allow everyone to be more innovative and think about budget, too.
- The medical framework doesn’t reward or incentivize meaningful engagement.
- Staff anticipates needs rather than allowing needs/interests to emerge in relationships.

Inability to Separate Health Issues vs. Aging Issues

- Aging is viewed as a health issue rather than a developmental issue.

Different Contexts of Care: Home Care, Adult Day Care, Institutional Care

- There are not enough support services for caregivers.
- There is a lack of education about what support services do exist.
- More effort is given to things that provide data for the system.
- Society doesn’t value caregiving; as a result, no relief is provided for caregivers.

Lack of Resources

- People don’t have access to tools.
- Art therapy is always cut during a financial crisis.
- There are few advocates for the arts.

Age Branding

- Geographic segregation inhibits intergenerational interaction.
- Stigma/bias inhibits innovation and change.

How Can We Overcome These Obstacles?

After we identified obstacles, the groups brainstormed ways they could overcome them. Note: the discussion became general here, so many of the bulleted points can apply to several categories.

Money and Time

- Demonstrate the economic viability and efficiency of transformed activities.
- One arts program was said to have saved a facility \$90,000.
- Create and support leaders who understand/value innovation.

Inability to Separate Health Issues vs. Issues

- Change the organization to center on the person.
- Look at enrollment forms, job descriptions, and evaluations; all of these items focus on the medical model. Flip these tools to emphasize the person.
- Create universal skills so all employees can assist with cares and be part of the "activities" through their relationships.
- Change assessment tools to those that capture what success means.
- Create a flat organizational structure.

Different Contexts of Care: Home Care, Adult Day Care, Institutional Care

- Engage the spirit of the individual as well as the caregiver.
- Caregivers should be valued by families.
- Create a peer support network for caregivers.
- Create a system to measure the quality of life.
- Suffering shouldn't be kept private, but should become shared so people can work together to end it.

Lack of Resources

- “Evangelize” quality of life – market/promote it as being as integral to the medical framework.
 - Get creative about reaching people so they can care.
- Don’t just offer tools; show people how to use the tools.
- Caregivers should share their stories with others.
- Recruit a diverse range of talented people into elder care.
- Stop blaming others and become a leader.
 - Support for leaders can come from older people, professionals in the field of aging, and caregivers.
 - Get the baby boomers to speak up. Lawmakers are asking if this is such a big problem, why aren’t they hearing anything?
- More advocates are needed for ourselves and our family members. Train a volunteer corps of advocates for quality of life among elders modeled on the disability movement.
- Use the theatre/arts network as a vehicle for aging education.
- Encourage people to reread the regulations – know more than your regulator and insist that they work with you to focus on Q of L.

Age Branding

- Help to change people’s ideas to a generalized interest rather than an individual self-interest.
- Lessen older adults’ fears about the younger generation and vice versa.

“In every setting, at home or in institutions, key elements of actualizing this potential are:

- Prioritizing more than physical well-being, giving equal weight to quality of life in all dimensions.
- Eschewing or supplementing assessment tools and standards of judgment that privilege what is easy to measure while omitting the deeper human story.
- Valuing and making use of creative individuals such as well-trained community artists, who naturally work in these ways.
- Hiring and supporting people with the necessary outlook and sensitivities to work with those in need of care.
- Supporting partnership and leadership at all levels.”

- Arlene Goldbard

Day Two: Public Forum

The next day, 40 additional people joined the Think Tank participants to challenge and develop these ideas. The new participants came from a variety of backgrounds and were invited to ask questions, share their experiences with older adults, and build on the ideas presented at the Think Tank.

Take-Away Ideas

To catch up the new folks, the Think Tank participants shared what stood out to them from the previous day's discussion. Here's what they said:

- From the enchanting activities, "Clipping coupons", the participants would go to the store and tape the coupons to the products.
- The privatization of suffering. Society expects us to keep suffering behind closed doors, as a private rather than a shared event.
- The whole idea of taking an idea and making it magical. Thinking about it as we did in a care setting makes it easy to do.
- I thought it was interesting that you're a person, and then there is a mix of something, then you become a non-person at a certain age. What is that mix?
- One of the other small groups was talking about how to support people and observed that people are afraid to fail in new ways.
- We all know what we want and what we should be doing. Why are we stuck and continuing to create situations and services that we wouldn't use? We have to begin to create services and opportunities for engagement that we would want to do.
- The mindfulness and sacredness of space around the table. We kept approaching the topic of mindfulness and spirituality, but just scratched the surface.
- How do we envision intergenerational work? How can we involve both older and younger generations in these ideas?

Question from the Public Forum Audience:

"Did you have older people in your groups, people who have experienced aging and disabilities? I am blind; I can see, but not read. What's that like? You need to have older people in your groups speaking with you. It takes a lot of time to have an older person speak. Think about having older people who are getting older and losing things they've had all their lives. Get older people into the system, make them comfortable, and get them to talk."

- Gwen T. Jackson

Synopsis of Group Activities

The small groups that created “enchanted” activities from the previous day were asked to think about them more deeply overnight and present them to the Public Forum audience. The ideas for enchanted activities evolved overnight, and we include here those activities that changed from one day to the next.

Folding Clothes

Take into consideration traditions of other cultures. Like Osoji, the Japanese tradition of cleaning the surface.

Are there chores that don't exist anymore because of technology? Discuss those chores while you are doing other chores, or reenact those “disappeared” chores.

Sorting Silverware

“When I first saw ‘sorting silverware’ I thought, ‘That is REALLY boring.’ But then we came up with this whole plan to make it a fun event!” – Will Reichardt

Sorting silverware can be a mechanism for connection among different people. People won't connect through the act of sorting (doing), but through the act of engaging (talking, sharing).

Coming together to sort silverware can be meaningful for some people. The entire group could come together to share a meal and decide what the meal was going to be. They could also design the invitations together or cut things out of a magazine to create an invitation collage, and this could be echoed by simultaneous communal events around the world.

Another suggestion was getting groups of people sorting silverware and preparing for a meal around the world. There could be webcams on the people sorting silverware, and on people metaphorically sharing in a meal. Instead of silverware, the group could sort something from another culture, such as chopsticks. This would help to take the mundane task of sorting ordinary silverware to a new level, helping people learn about traditions in other cultures and to share their own traditions.

Going for a Walk

Put stop gaps into the walk. (Stop on purpose to look at something.)

Take a digital camera with you to take pictures of certain themes. (Birds, colors, favorite plants, etc.)

Later, discuss the pictures and why they were taken.

Scrapbook the pictures taken on the walk and create memory books of your walks.

Bring in experts on birds and plants to join you either on the walk or for the discussions of the memory books.

Draw a map of your day, including the walk. This could serve as a tool for discussion and engagement.



“I learned that boring, everyday tasks can be changed into something exciting by making them engaging.”

– Will Reichardt

Listening to Music

This project could be expanded to include different generations. Choose music that is memorable to the older generation and then have young musicians come in and remix the tracks.

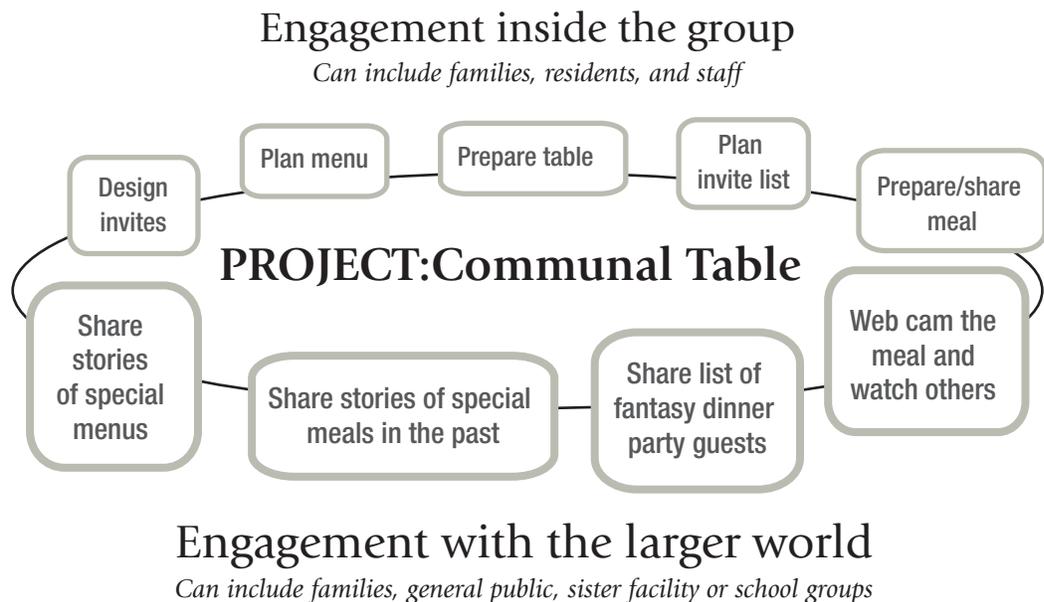
Explore what music does to the brain.

Do a TimeSlips storytelling session using music clips as prompts instead of images.

Use a method called "Songwriting Works" to write a song with a group of people.

Summary/Model

Each of these small projects was transformed into something larger, with meaningful points of engagement for family, staff, and residents as well as meaningful points of engagement for the participants and the larger community/general public. The model for these types of projects looked like this:



Synopsis of Focus Groups

In the previous day's Think Tank, participants identified four key avenues for changing activities in long term care. The small groups that tackled these issues the day before were asked to think on them overnight and present them to the Public Forum group. The groups were: staff education, family and friends' education, re-branding aging (in general), and forging partnerships.

Staff Education

The question we posed was, "How can we grow a caring community?"

Another question we asked was, "What about caregivers from other cultures?"

What is needed are tools and techniques that grow the movement.

We need to utilize team-building practices.

We need to create online caregiver trainings.

We need to create a setting in which people will be comfortable with a range of different answers.

Family and Friends Education

This group had people from different fields in it – theatre, music and professionals from the aging community. The question they chose to answer was, "How do family and friends cope with difficulties and hardships when their loved ones aren't in a formal care setting?"

The participants saw these problems:

- There is no guided conversation; if a family/friend reaches out for help from a social worker, they are linked to services, not conversation.
- There is no formal assessment for family caregivers working with people diagnosed with dementia.
- There is no training in the arts for social workers.
- There is no category for the arts or arts programs in the services provided for home caregivers.

After identifying these problems, the participants shared these solutions:

- Activities training could give social workers the tools to have a guided conversation to identify the appropriate activities for the individual and caregiver.
- There should be a category for the arts programs provided for family caregivers in listings of aging services.

Re-Branding Aging

Branding is defined as shaping people's perceptions of a product or person; branding is linked to ageism, since it is based on people's experiences and perceptions.

People's experiences and perceptions are often shaped by the media. For example, the older person is often portrayed as being weak, weird, or as hyperbole (the 87-year-old man who jumps out of an airplane). In fairy tales, older people are also commonly the villains.

This group asked the question: "How does one go about re-educating the media?" The answer to this question is to work with the leaders of the media to show them that it is a smart business strategy to show diversity in aging. The participants also pointed out that it would be beneficial to present the data on how businesses portray older people.

Another solution to this problem is to have a grassroots advocacy campaign. Society needs to see older adults functioning within society. It is possible to use social media to recruit and educate people from all walks of life and boycott products that portray older people in a negative way. Older adults should lead this charge!

This group also asked, "What sort of images do we want to see?"

- Expose the current negative imagery by using humor. (One example was to create a commercial in which an older woman picks up a stapler, thinking it is a telephone.)
- Write sarcastic letters to television stations thanking them for their positive portrayal of the older population.
- Create a public service announcement in which older adults connect to younger age groups. The older adults would be talking about something they believe in besides aging, such as green living and the environment.



Partnerships

This group defined partnerships as when individuals remove all distinctions of age and get something from the relationship; and as having equal parties coming together to perform a task. They stressed the importance of intentionally excluding age descriptors when describing partners or task force members.

The group asked three questions regarding partnerships:

Who are potential partners?

How do we go out and get them?

How do we sustain them?

A partnership could be created through:

- Inviting artists in residence to your facility who are willing to add meaning and growth to their work.
- Using an organization that matches people with places, such as AmeriCorps, Public Allies, etc.
- Involve high school students through service learning programs. (The students could gain knowledge through a partnership with an older adult.)
- Connecting with AARP civic service engagements or other volunteer programs (like RSVP).
- Museum education projects.
- Creative and performing arts projects.
- Inviting cooking school students to test their recipes at facilities by cooking for the residents.
- Creating e-mail pen pals.
- Creating technology buddy systems.



Questions from the Larger Group

At the beginning of the Public Forum, Basting invited each of the participants to write down any questions or observations they had on post-it notes placed at their tables. They would then place the post-it notes on the wall behind the podium. Later in the forum, Basting read the questions and the large group addressed them.

Post-It observation: Let's never forget that the core of transforming activities is changing from entertainment to engagement, and that means we must develop relationships with people so we understand what and how they want to be engaged.

Post-It observation: "Great ideas! I wish there were taxonomy or a catalog to link them."

Post-it question: "Across the projects that we've identified, where is diversity, LGBT or people of color?"

Assessments at intake are most commonly done from a heterosexual perspective, asking people if they were married and had kids. We need to be more aware that this isn't appropriate for everyone. It's important not to overlook, however, that some LGBT people *have* been married before.

Congregate care settings need to get to know their residents and what they are interested in. There are also specific layers of staff at these facilities. Facility staff should address intergenerational issues. They should learn how neighborhoods or people shift culturally and then bring in people of that culture to help address those issues.

"For everyone, some key needs are:

Reframing our understanding of aging, so that people are not written off as their capacities change, but continue to be seen and valued as whole persons;

Transforming media portrayals of aging to convey this deeper understanding;

Transforming aging policy at every level, reversing the privatization of suffering to bring about a public culture of care and support."

– Arlene Goldbard

Sample intake questionnaire (with answers from a Think Tanker) used by Luther Manor Adult Day Care to get to know their residents' individual interests in order to apply them to activity planning.

20 Questions for Elder and Dementia Care

(Designed by Lyn Geboy, Ph.D.)

Name _____

Nickname _____

Favorite season: Paprika

Favorite thing in nature: sloths

Favorite sport/physical activity: Riding my Bike

Favorite hobby/pastime: Cooking

Favorite place to visit: Las Vegas

Favorite holiday: Thanksgiving

Favorite pet/animals: Basset Hound

Favorite snack: Gas Station Fare

Favorite song/type of music: The ABC's

Favorite restaurant: Sakura Sushi

Favorite food to eat: Oysters

Favorite day of the week: Saturday

Favorite subject in school: Psychology

Favorite thing to wear: Stocking Cap

Favorite thing I own: The Man Van

Favorite room in my house: Kitchen

I always dreamed I could be: Lots of different things

What I did for a living: Artist

Favorite job: Cab Driver

Something I'd like to learn is: Piano

Breakout Projects

For the final section of the Public Forum, Basting introduced the “Bold Idea Tables”. “In the Think Tank,” she said, “we focused on concepts, philosophies, and vision. In order to put those larger concepts into projects we need your help today. Let’s see if we might get concrete about how to address them.” Basting then assigned each table a Project to brainstorm and then present their ideas to the larger group.

Project “Meaning”

Questions to be answered: We observe that “activities” for older adults tend to be busy work, and we say that they need to be MEANINGFUL.

- What does that mean?
- How do you make sure something is meaningful?
- NOTE: There is some writing about this among scholars/practitioners...but NOT ENOUGH. We can really define it here.

- Tailor the activities to the person’s interest to make the activities individualized.
- Remember, the purpose of activities is engagement; to connect with other people.
- Gather feedback from the individual about whether they thought the activity was meaningful.
- Create a different approach for assessment of the individuals in a nursing home or home care setting that addresses meaningfulness.
- Improve observation skills of caregivers/family members, so they might be able to interact with the older adult in a meaningful way.
- Create activities that focus on engagement, but that also result in a product; something to take pride in at the end.
- Realize that “personhood is not just about an individual with dementia, but about a relationship with others (staff, family, friends).
- Go beyond surface questions or responses. Connect to the larger community.
- Remember that being involved in the process, the moment, the pleasure of doing the activity can make it meaningful.
- Assert that engaging with older adults at home or in a congregate care setting benefits caregivers, staff, and family.

Project “Words”

Questions to be answered: The very language we use to talk about activities seems to be part of the problem.

- Why do we use the word ACTIVITY?
- Do we need it? Why? If not, what might we use?
 - The connection between people should be the focus, not the activity.
 - Inspectors want to see activity calendars. Why not have a larger project that creates an activities curriculum?
 - Teachers differentiate the curriculum to the needs of the people; we should focus on abilities, not disabilities.
 - Have fun with language when brainstorming names for activities; for example, change the activity name, “Exercise class” to “Bust a move!”

Project “Being vs. Doing”

Questions to be answered: As a culture, we heavily value busy-ness and productivity. How can we come to value contemplation and states of being rather than doing? What do we do with the time we have been given?

- As an intergenerational project, write up a time log sheet that shows what is being - done with the time we have as a lesson in how we use our time.
- Practice just being in the company of others.
- Share with others the value systems of other cultures.
- Realize that older adults have time: What is the way to share this with others?
- Inspire each other to realize that “Being” is Productive.

Project “Us vs. Them”

Questions to answer: We talked about the need to have everyone imagine their inner elder so that issues of engaging older adults become shared concerns. Create a project that emphasizes the inner elder in all of us.

- Try walking in someone else’s shoes; Try wearing glasses like somebody else’s for a day.
- Think about what sorts of things you could wear to change the way you see or hear the world.
- Realize that asking for help is something that most people dread doing.
- Interact with graciousness. Treat all people as you would like to be treated.
- Create public service announcements that profile older adults. For example, make one about what you have to do to have a school named after you. (Center Street School is going to be renamed, “Gwen T. Jackson Early Childhood Education Center.”)

Project “Capitalism”

Questions to be answered: We talked about this on multiple levels – 1) the health care system doesn’t value quality of life, but disease treatment and management, and 2) capitalism values productivity – older adults are imagined to lose their “capital” when they leave the workplace (or sometimes while they are still in it).

- What kind of a project might you create to assert the value of older adults in a capitalist system?
- What kind of partners might you work with?
- One example from yesterday was an adult day center activity that had older adults clipping coupons and then taking a field trip to a grocery store where they taped the coupons to the items for others to use. (*Note: We thought this was brilliant!*).
- You might also imagine a project that addresses this point, asserting the value of quality of life as equal to (or greater than) disease management – particularly at the end of life.

This project imagined the arena where they would present their ideas: To the law-makers in Washington, D.C. Using this arena, this project aimed to:

- Juxtapose a profile of members of congress with people from the aging community. Use this to recognize members of the aging community and show their contributions.
- The goal is to change the public viewpoint. AARP could be used to increase visibility.
- We could use insurance companies to move towards wellness and community.

Project “Resources”

- We talked about the need to share resources about ideas and frameworks for doing “activities” that are meaningful and connected to the larger world.
- Create a list of ideas for what those resources might be, where those resources could live, and how multiple groups (artists, community organizers, aging services providers, students, etc.) might know about and access them.

This project recognized that there were resources out there, but these resources weren’t easily accessible. People need a new, easy way to access these resources.

Use www.epicurious.com model

- Categorizes matches by either highest rated, or newest match
- Offers users forums to discuss and swap ideas
- Be sure that “arts programs” are a category

Note: see the appendix for an extended list of resources.

Project “Shared Stories”

Questions to be answered: We talked about the notion of the “privatization of suffering,” and of how sharing our stories (of both pleasure and loss/challenges) can bring us out of isolation and back to community.

- Create a project that shares the stories of the experience of late life. Which stories?
- How are they shared? Who do you see as your audience?
 - Older adults’ stories become private; find a way to share their life stories and what is important to them beyond any illness they might have.
 - Give the stories universal themes and frameworks, such as journaling of experiences, answering the question, “At what point did you realize you were aging?”
 - Use various forms of art to create the story from individuals.
 - Make connections between people and their stories to build community and relationships.
 - Develop partnerships to share stories in the larger community.
 - Ask the individual, “How do you want your life to be remembered? How do you want to be remembered? Your impact on the world to be remembered?”
 - Engage organizations and different sectors to share stories, such as media and schools.
 - Write a humorous book about aging, one title suggestion was *Survival Guide for Your Inner Elder: Aging is Not For Sissies*.
 - Follow a “valued aging” model. Valued aging models include interdependent family and community relationships that exist as more than dependent and independent relationships. These valued aging models are used by other cultures.
 - Use the idea of “social riches,” whereby everybody watches out for everybody else in a neighborhood setting.
 - Write the story of the neighborhood that shows the contributions of diverse range of people using a “beat cop”-like approach. Show the positive relationships between individuals in the community, such as how the individuals in the community look out for each others’ safety.



Project “Leadership”

- We talked about the need to groom, recognize, and support leaders who advocate/fight for transformation of activities for older adults.
- Create a project that recognizes and supports the effort of leaders – be they older adults, long term care workers, or family members.
- Example: How do you find them? (Partnering organizations?) How do you tell the world about them? What kind of support do they need?

What is the difference between born leaders and appointed leaders?

- A leader is someone who has an idea and grows it into something larger than themselves
- Grow a core of volunteers and use celebrity influence to help cultivate and support leaders

There are recognizable leaders in the older adult’s community; such as the actor Clint Eastwood, and Senator Robert Byrd from West Virginia. It is important that society hears the voices of these older individuals and see their faces, recognizing them as leaders.

Project “Education”

Questions to be answered: We talked about the need to bring these ideas (of meaningful engagement through the arts and “activities” and its root – person-centered care) into the hands of the long term care workforce and to families/friends/older adults themselves.

- The groups are very diverse (a big challenge!) – so think about it in terms of your own expertise/position.
- What might be a really great, accessible way to get this information to YOU or the people you work with?
 - Partner with groups who have built-in audiences, including groups you haven’t even thought of going to.
 - Many individuals serve the elderly; have people from all walks of life come and speak about their part in caring for the elderly.

Project Education also recognized that there was no clearinghouse to get their ideas out to the public. Their solutions to this problem were:

- Get the information out either by distributing them in print, or publishing them online.
 - A second stage clearinghouse would be to go out to the community, to churches and community centers where activities and projects could be used to get the information out to the public.

Project “Enchantment”

- We talked about the need to “enchant” the lists of recommended activities. We interpreted enchantment as making the activity more than it seems – adding something almost magical to it.
- Pick one (or more) of the activities on the list of 101 activities recommended for people with Alzheimer’s (from www.alz.org) and enchant it.
 - Make each of the activities into a project. For example, sanding wood is a project.
 - Use each of the activities to make something of value.
 - Recognize personal expression as a value.
 - Expect the best from people’s projects and help only if necessary.
 - Work in teams with varying abilities.
 - Stop imposing on older adults our ideas about what we think is right and how things should be done.
 - The example was the project of a visual artist. He set up a cage filled with wild birds and invited the members of the community to come and release a bird into the wild from the cage. The artist warned the community to carefully think about releasing the birds as it was the middle of winter. Some people came out and thought it was best to release the birds into the wild. These birds were fine for a few days, but soon died due to the cold weather and lack of food. The artist pointed out to the community that what they thought was right for the birds actually brought harm to the birds instead of helping them.



What are your thoughts on “Activities”?

Visit www.aging.uwm.edu and let us know.

Resource List

General Information

Alzheimer's Association 1-800-272-3900; www.alz.org
American Association for Homes and Services for the Aging; www.aahsa.org
American Society on Aging; www.asaging.org
"Aging & Life Course, Family & Community Health"; www.who.org
U.S. Administration on Aging, Elder care; www.eldercare.org
National Adult Day Services Association, www.nadsa.org
PHI National, Quality care through quality jobs; www.PHInational.org
Pioneer Network: Changing the Culture of Aging in the 21st Century; www.pioneernetwork.net
Richard Taylor, Ph.D.; www.richardtaylorphd.com

Caregiver Programs and Support

Today's Caregiver magazine; www.caregiver.org
Aging Care: The Community for Caregivers; www.agingcare.com
Senior Services; www.seniorservices.org ; (Washington state program)
Family Caregiver Alliance; www.caregiver.org
National Family Caregivers Association; www.thefamilycaregiver.org

Activity Ideas

Model Arts Programs

ArtCare, an artist residency program at Luther Manor Adult Day Center; www.luthermanor.org
(414) 464.3888
Arts for the Aging (AFTA); www.aftaarts.org
Artists for Alzheimer's (ARTZ); www.artistsforalzheimers.org
The Center for Elders and Youth in the Arts (CEYA); <http://ceya.ioaging.org>
Elders Share the Arts (ESTA); www.elderssharethearts.org
Memories in the Making; http://www.alz.org/oc/in_my_community_10166.asp
Museum of Modern Art; www.moma.org/education/moma_access.html
National Center for Creative Aging (NCCA); www.creativeaging.org
Songwriting Works; www.songwritingworks.org

Arts Ideas/Information

Community Arts Network ; www.communityarts.net
Instructables; www.instructables.com/
Got Character?; www.gotcharacter.com.sg/;
Learning to Love You More; www.learningtoloveyoumore.com
Squiggles Books; <http://childrensbooks.about.com/od/productreviews/fr/squiggles.htm>

Creative Movement/Improv

DanceWorks; www.danceworks1661.org

Kairos Dance Theatre; www.kairosdance.org

Liz Lerman Dance Exchange; www.danceexchange.org

Next Stage Dance Theater (NSDT); www.nextstagedance.org

Applied Improvisation Network; www.appliedimprov.ning.com/

Story Telling Resources

StoryCorps; www.storycorps.net

Storybook Online Network; www.storybookonline.net/

Life Story Center, (University of Southern Maine); www.usm.maine.edu/olli/national/lifestorycenter/

TimeSlips Creative Storytelling; www.timeslips.org

Intergenerational Activities

The Intergenerational School; www.tisonline.org

Neighbors Growing Together; www.intergenerational.clahs.vt.edu/neighbors/index.html

St. Ann's Center for Intergenerational Care; www.stanncenter.org

Elders Share the Arts; www.elderssharethearts.org

Memory Bridge; www.memorybridge.org

Other Art Projects

Duplex Planet; www.duplexplanet.com

Canadian Centre for Architecture (CCA), tools for Action; <http://cca-actions.org>

Mini:mentals; <http://www.minimentals.net>

Post Secret Blog; <http://postsecret.blogspot.com/>

Indexed; www.thisisindexed.com/

Talk Back Move Forward: 100 Years of Alzheimer's Disease; Produced and Directed by Dr. Anne Basting; www.aging.uwm.edu

To Whom I May Concern, (a performance piece); www.towhomimayconcern.org

Photographer Wing Young Huie; www.wingyounghuie.com

Educational Activity Ideas

How Stuff Works; <http://www.howstuffworks.com/>

Book Glutton: The Unbound Reader; www.bookglutton.com

Math Moves U; www.mathmovesu.com