

# TUE MAR 22 Mapping Perceptions

## The MoMA Alzheimer's Project Summit

**The Grand Scale: New Frontiers** invited Summit participants to think broadly about the future of dementia, art, and learning. Using the [Open Space](#) facilitation method, participants suggested discussion topics based on their own areas of interest and expertise, and then broke out into smaller groups to further explore these ideas. Participants in each of the small discussion groups took notes on the exchanges, the results of which are below.

### Big Theme: Training of Health Care Professionals and Carers

#### Sub-themes:

- ★ Programs for caregivers
  - ★ What is the role medical schools can play in advancing this arena?
  - ★ How do we change attitudes in long-term care facilities?
  - ★ Training healthcare professionals in visual inquiry (educators especially)
  - ★ Partnerships between museums and hospitals or adult day care centers/nursing homes
- Role of medical schools:
    - ~ Inform students of the role of art in treating patients
    - ~ Increase humanistic emphasis and inquiry
    - ~ Improve visual cues, and observation, ability to describe those experiences
    - ~ Emphasize importance of empathy
    - ~ Improve collaboration
  - Need for evaluation/metrics of this M.D. humanistic approach
    - ~ Defining the value through evidence-based methods
  - Greater emphasis on the part of museums to understand current medical trends/issues of concern
  - Geriatric education centers where health professionals combine cultural and life practices (e.g. Learning how to fall through dance)
  - Partnerships between museums and hospitals and adult care centers
    - ~ Cleveland Clinic
    - ~ RISD



programs combining  
both
  - The role of intergenerational groups to facilitate med. school experiences and perspectives
  - Breaking down biases at the highest level of medicine that the benefits of art are “soft science”

- ~ The “lost generation” project in Australia where benefits were evaluated through film/video
- ~ Select thought leader/ advocates telling the story
- What are the right instruction(s) to educate caregivers on the augmenting aspects of art for this population, and related benefits?
  - ~ Museum caregiver support groups
  - ~ Can museums be an effective messenger through websites and other free resources?
  - ~ Modelling of an “engaging experience,” role of the imagination etc.
  - ~ The role of online courses as another medium to educate caregivers
  - ~ Medical students, perhaps paired with Columbia’s model art and medicine program
  - ~ “Creative intervention” internships to model and evaluate efforts
  - ~ Khan Academy (online/free) – style courses for this population

## **Big Theme: PR/Cultural Change Awareness**

### **Sub-themes:**

- ★ Getting new research to public
- ★ How can we change the perception of aging from the ground up? Starting with children?
- ★ Stigma Reduction!
- ★ Policies regarding outcome for care
- ★ Being more prepared
- ★ Shift in values respecting older generation
- ★ How to make more “dementia friendly” communities
- ★ Moving away from fear tactics and language
- PR/ Cultural Change
  - ~ SEA Change – Gene Cohen  
(Societal Education about Aging for Change)
  - ~ WHO – April 7, 2012 – Aging
  - ~ Alzheimer’s Awareness Week
    - Global calendar of events. Awareness.
  - ~ Memory Bridge – Chicago – Children’s Afterschool Program
    - Learn@self, identity
    - Buddy system
  - ~ % of research funding – Stigma Reduction
    - Public awareness
  - ~ Advocacy Groups
    - Cooperative efforts
    - Education and public awareness campaigns
  - ~ American Heart Association model/multi-disciplinary efforts
  - ~ SPARK! Model
    - Collaboration and shared resources

~ Family friendly – dementia friendly community

## Big Theme: Museums & Community

### Sub-themes:

- ★ The Participatory Museum
- ★ How can museums attract more first time visitors? And how do we maintain interest?
- ★ Arts finders collaborate with social service finders.
- ★ Building Community Through the Arts (BCA)
- ★ A special museum/gallery for art made by people with A.D.

## Big Theme: Art & Life

### Sub-themes:

- ★ Arts infused into everyday life
- ★ Creative approaches to daily life
- ★ Increased integration of the arts in programs serving elders
- ★ “Art” visits to other forms of art – music, dance, photography etc.
  
- Viral messaging –
  - ~ More grassroots outreach
- Use media – power of storytelling
- ‘Tell a story – hear a story’
  - ~ Unlikely partners (Beauticians, postal worker...)
- Positive imagery
  - Empowered + Complex + Interesting

## MUSEUM POSSIBILITIES

**Post-it:** Ways to bring more early diagnosed visitors and their caregivers to the museum

- Considerations:
  - Spouses, work, weekends, crowds
  - Denver: early onset visitors
    - Fri. Afternoon, 1:00 -2:30pm, coffee
  - We need our marketing people to help?
- Creating universal programming targeting the adult audience
- Active Minds Programs– independent programming (not affiliated w/ museums or university) maybe? Normalising the tour created for the Alzheimer’s audience
  - ~ Problem here is training again

**Post-it:** How do we train museum educators to work with this population?

- Alzheimer’s Association

- Local Senior Care Centers may be willing to provide training for your staff at their facility
- MoMA!
- Local Alzheimer's Disease Research Center to talk about clinical side

**Post-it:** Make programs “with” not “for” person with dementia

- The Penelope Project (use as an example/model)
- Advisory Council (create one to research-advise how to involve the person with dementia in planning process)
- Focus Groups

**Post-it:** How can art bring different segments of society into relationship?

- Intergenerational approach
  - ▶ School
- Pairing young children with elders
- Pairing college students with elders – not cognitively impaired – opened up college class to elders to AUDIT class

**Post-it:** Arts programming in addition to this or alongside this for:

- Other elderly groups
- Other cognitively-impaired groups
- Is this an opportunity to cast a wider net? With this programming, do we have a chance to open this to other cognitively impaired groups?
- Problems:
  - ~ Training staff, Docents
  - ~ Different (very) cognitive abilities
  - ~ Can't 'lump' these audiences in the dementia group

## **Big Theme: Intergenerational**

### **Sub-themes:**

- ★ Intergenerational workshops on philosophy and ethics
- ★ Universal design – what's good for one audience may be good/useful for all audiences – is this possible/plausible?
- ★ Arts education includes community-based work as normal
- ★ Intergenerational art tours – how feasible to implement? What are benefits?
- ★ Goal: Intergeneration awareness of dementia and support and respect for our elders
- ★ Intergenerational program for AD people
- ★ Global climate change/intergenerational disaster ethics
- ★ Intergenerational learning center
- Environ. challenges for future, how art can help us imagine a more hopeful future.
- Climate change is an intergenerational issue

- Teachable movements around disasters. Drastic changes
- Elders teaching youth how to build upon how to deal w/changes that happen, teaching from their experiences
- Technology, how older people maintain respect?
- Putting elder back into center of community
- Hospitals w/Holocaust survivors – Jewish HS students come and interviewing
- Learning through talking through learning from others
- Steps to making intergenerational included and large scale
  - ~ Generations United and Center for Generational Learning
- Intergenerational learning environments in communities in future
- Generating community
  - ~ Flushing
  - ~ Youth & Elders creating play
  - ~ Millennium Art Academy
- Replaceable is community partnerships
- Accessibility w/resources
- Need examples to show models and what works
- Getting stories out
- Distance and logistics, how do we construct cities/communities? What is accessibility?
- Used to be family centric, families now more dispersed. Extended families not living together – older adults “adopting” children
- Schools at heart of these communities
- Thinking about ways to create environments – activism that is not pleasurable is not sustainable
- In Ontario, HS students doing mandatory service hours – music programs: Jazz for Juniors/Spirited Seniors
- Evidence is hard because mostly anecdotal
- Story Corps – Elementary school kids interviewing grandparents
- Form bonds and relationships outside family, important pearls of wisdom – don’t talk to families, story sharing
- Museum intergenerational programming?
  - ~ Not expensive and easy to do
  - ~ Captive audience, natural opportunity
  - ~ Educator’s job: differences, not a big deal
  - ~ Creating of level playing field
  - ~ How do you take advantage?
- Constraints in resources in future?
  - ~ Efficient
  - ~ Step back to look at training
  - ~ Understanding different groups and aging process
  - ~ Japan – elderly and kids most susceptible – disaster preparedness programs
  - ~ Money for intergenerational building, government looking at but not so much evidence
- What is art?

- ~ Outside art into aesthetics of everyday life – outside MoMA
- ~ Farmer's market in hospital

## **Big Theme: Caregivers/Training/& Access to Resources**

### **Sub-themes:**

- ★ Changing caregiver models to include engagement
- ★ Providing access to individuals who are reticent to be part of a group/facility/organization
- ★ Access to resources in rural communities (how to transfer/transport these great initiatives)
- ★ Empowering staff (CNAs, nursing, ancillary staff) as part of culture change
- ★ Scholarships for training caregivers in nursing homes, home care in creating are to people with AD

## **Big Theme: Diversity/Intergenerational**

- Volunteer program – having purpose, feeling valued – how do you invite to become volunteers? Engage in the doing?
- Use social structure to engage people of variety of abilities
- Encourage volunteer opportunities
- Not enough opportunities out there
- Safe structured environments invite opportunities to emerge
- Engage volunteers through professional development
- Professionalize the work
- Expectation developed through volunteers
- How do you develop ground for opportunity
- Using network to branch out and recruit volunteers – personal networks to bring in people w/ dementia to participate AND volunteer
- Safe for volunteers to do this work
- Open up trainings to more than just staff
- Create opportunities for young and old
- Think about people – what's needed to change perception and stigma
- Think about areas where range of volunteer possibilities and work with who's in charge of organization to facilitate this bridge
- Bridge between departments and communities
- Focus in on individual's strengths and weaknesses
- Any institution with strong volunteer programs should question
- Develop volunteer program that reaches out to young people team – young and older people together in pairs
- Build community programs school and seniors in museums (safe space) and educate about each other
- Art becomes vehicle for magical opportunities
- Asking questions to remove fear – create situation for safe questioning

- Job descriptions – be specific about what you want volunteers to do – this is gentle way to involve people with dementia
- Grandparent/grandchild programs – interviewing one another – make use of familial connection
- Train young people to feel comfortable with older generations
- Engage people with Alzheimer's to be active part of the process
- Find opportunities to make room to recognize strengths – reach out to others to make it work for ALL volunteers
- Ask volunteers/staff about who might engage in this specific way
- Start asking people to branch out to their own networks

## **Big Theme: Museums & Community**

### **Sub-themes:**

- ★ Combining the “Arts” (music, poetry, painting, writing, sculpting etc.)
  - ★ How can we reach more people of color?
  - ★ Volunteer programs that engage and invite people with varying levels of cognitive abilities (specifically arts organizations)
  - ★ Creating real ownership in the minds and hearts of the consumers whose culture you and others want to change/improve. How do you change yourself and how do you change the consumer?
  - ★ Intergenerational learning and the idea of “cross-pollination” of learning
  - ★ How do we bring generations together?
- 
- Intergenerational and participatory activities
  - Use technology – digital booth, dialogue, videos
  - Get comments from participants to see artworks – place comments under “artwork for others” to see. Use post-its. Humanising the process
  - 20 piece small gallery of art made by people with AD
  - Partnering with other community agencies – i.e. libraries, artworks, schools.
  - Advocacy for mainstream venues – movies, plays to help promote the cultural change of AD
  - Change the name – not scary or depressing
  - More collaborations between resources
  - Using the person with AD – assisting the museum educator/leader
  - Changing/educating Police/Fire Department
    - ~ First line
    - ~ Incorporate these services – through museums/cultural institutions
  - African America
  - Hispanic outreach through Alzheimer's Associations
  - Try to find ways to foster dialogue so that there are forums to speak about dementia
  - People come to museums first before support groups
  - Build in supports people don't know are there

- ~ Ex. open house to facilitate access, allow experience to happen so more likely to join specific programs later on
- Create strong foundation to think about ALL people
- Power of word-of-mouth
- Let participants bring artwork home

## **Big Theme: Museums, Art, History**

### **Sub-themes:**

- ★ Universal access? Diverse audience sharing/learning together
  - Age – diversity
  - cognitive ability – diversity
- ★ How can museums take on these programs to offer them to everyone – not just 10/100 at a time? There seems a fear that this idea will get away from us and this in all we will do
- ★ How do we make the experience at the museum a better experience?
- ★ How do we extend the experience beyond the doors of the museum?
- ★ Share ideas for art-making
- ★ Consider ways to use history as well as art as a basis for programs
- Art - looking and making programs
  - ~ On the same day
  - ~ Multi-visit sessions
  - ~ Early – moderate stages of memory loss
  - ~ 1-1¼ hours for time
- Intergenerational teaching/learning
  - ~ Gallery teacher – trains as museum educators from variety of fields – Public Health, Art History, Psychology
- Walker Art Center: self selecting group of volunteers – (10) who come from variety of fields –
  - ~ Group relationships – come 1X a month
  - ~ Some of volunteers do all of the questioning
  - ~ Partnership between some staff, visitor services, all involved
- What's missing – what can be addressed
  - ~ Training of all staff of instructions in needs of visitors – security
  - ~ ? that people can enter
  - ~ Chairs – elevators throughout
  - ~ Welcoming route
  - ~ We want to provide something to a community – but does audience get it when they walk through door?
  - ~ How to do PR so it's a clear message and desired program for audience and institution – assumptions & disconnects in partnerships – outreach
  - ~ Universal design in programming and physical space
  - ~ What about people who don't have families etc – how do we serve individuals and other institutions?

- ~ How do we not focus on memory – then & now
- ~ Idea of storytelling and imagination

## **Big Theme: Culture Change & PR**

### **Sub-themes:**

- ★ Inviting the “friends” of those diagnosed with AD to learn more
- ★ How long should/will the information take to happen?
- ★ How do we shift public perceptions of AD?
- ★ How to capture/record information from good collaborations
- ★ Given that everyone participating in a program may have different levels, needs, how can you effectively engage everyone?
- ★ LANGUAGE: ex. care giver or care partner?
- ★ A mass PR campaign to educate the public
- ★ How does this conversation get to the “liveable communities initiative”?
- ★ How do you create the paradigm shift that needs to occur to get “community” talking about positive potential with Alzheimer’s disease?
- Absolute need for public awareness on broadest scale and with a positive message \
  - ~ Strategic-based
  - ~ Positive
  - ~ Celebrate living in the moment
  - ~ Proactive
  - ~ How do we change the paradigm?
  - ~ How do we promote everyone getting ? Memory screen?
- PSA to reach largest audience
  - ~ Need for corporate support
  - ~ Cautious of not over-selling
- Art of Caring
  - ~ Invite social agencies, churches, synagogues to be involved

## **Big Theme: Care in Community & Caregivers**

### **Sub-themes:**

- ★ Care-in-community, not nursing homes
- ★ Aging in place
- ★ How do we promote empathy
- ★ How can we reach people living at home who do not already make the arts part of their lives?
- ★ How can we acknowledge the importance of “living well” with AD – with the reality of the decline and care needs as people move to the middle and advanced stages?

- ★ People unwilling to come to “Art” programs because they are afraid to reveal they have memory loss in the community
- ★ How do we inspire caregivers?
- ★ Deconstruct and disperse nursing home functions and hierarchy into smaller “care” communities, use a village model. (Bill Thomas, Greenhouse model)
- ★ Encourage and promote Advance Directions
- ★ Recreating “family” supports with neighbours to promote Aging-in-Place
- ★ Improve distribution of resources
- ★ What are the opportunities for socialization and connections for caregivers, outside of support groups and other Alzheimer’s/dementia groups?
- ★ Using theater games to promote empathy
- ★ Ageism and ways to deconstruct
- ★ Grandparents raising grandchildren

## Big Theme: Government & Health Institutions

### Sub-themes:

- ★ How do we develop/sell leaders on these ideas?
- ★ Where do the senior service agencies fit into this conversation?
- ★ How can we engage local governments to change AD culture?
- ★ How can we transform the medical education culture from doctor-patient hierarchy to co-creative health learners and health instructors forming dynamic relationships?
- ★ When funding for basic support is in jeopardy, and Medicaid is threatened... Where will the programs that support QUALITY of life come from?
- ★ Promoting health, healing and recovery?
- ★ Geriatric education framing professional healthcare. Providers include artists
- ★ How can we engage local universities, health centers, doctors to work with the arts for culture change with AD?

1 Education

2 Service ?  
exhibition

3 Research shared space Newark – for ? IRB

4 Community doing research – Gold Foundation

} Katrina arts program, art

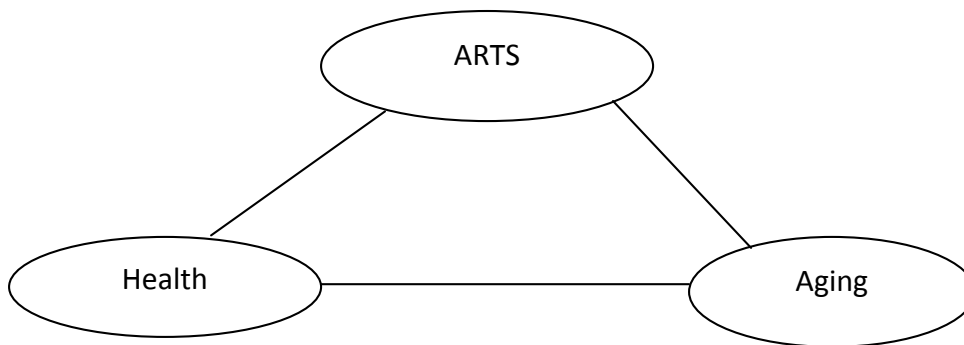
1 Education

2 Artists in Residence – one day

3 Service

- See if someone is interested (in) a campaign - including primary systems she sent healthcare (services)
- P.A.L.M. Foundation room – wellness, arts enrichment services, disabilities
- Synergy of people
- Pacific points:
  - ~ Oahu

- ~ Cleveland Clinic, OH – Meet Me – Cleveland Museum partnership
  - she is a curator; arts in healthcare
- ~ NY – University of Medicine & Dentistry of New Jersey –
- ~ NY – Libraries Communities need to find studies (Libertine Arts) research for systems change
- ~ Note: Healthy 2020
- ~ DC – NCCA ?? Systems
- Note: Gene Cohn
  - ~ On individual level – making it happen
- Note: need to talk about other arts
  - ~ Teamwork important
- Training for caregivers – paraprofessionals, family
- Need to change paradigm – person centered
- Problems –
  - 1 Healthcare turnover – at all levels
  - 2 Find open doors, support healthcare teams e.g. Falls
  - 3 Trust between Healthcare
  - 4 Coverage to do training for healthcare providers
- Three systems: Healthcare/Arts/Aging



## Big Theme: Training

- Instilling confidence in ability to interact
- Distilling conflict between caregivers and people with dementia
- Response of educator models tactics for caregivers
- Language differences? Standardization?
  - ~ Caregiver
  - ~ Consumer – boo! ☹
  - ~ Carer
  - ~ Care recipient
  - ~ Care partner
  - ~ Elder ☺
  - ~ Senior
  - ~ Über -boomer ☺
- Fantasy that training no longer necessary because culturally competent
- Idea of training as support/dialogue

- Institutional Resistance – getting staff buy-in and passionate personnel

## **Big Theme: Caregivers**

- Creativity through everything “cleaning the toilet can be creative”
- Equal participants in discussion and playfulness
- Decreased stress, informal support groups
- Training staff (e.g. CNAs, bus drivers) in programs
- Culture change – nursing home as “home” for increased socialization vs. Aging in place and potential for isolation
- Effective mechanisms for communicating training to CNAs, professional caregivers?
- Utilizing drama therapy for training – “Penelope Project”
- Reverse hierarchy

## **Big Theme: Access (Resources)**

- Challenge of reaching people who are not affiliated with a pre-existing program/organization – getting information to primary caregivers, primary physicians – include in resource packet with diagnosis  
\*Collection makes a difference\*

## **Big Theme: Museum Possibilities**

### **Sub-themes:**

- ★ Art Experience vs. Art Therapy
  - ★ Culture Shift: museums to Audience centered programming, care facilities to person-centered care – both huge challenges – at the overlap point may be dementia program – how can use to culture shift
  - ★ How do we create space in the museum to do these types of programs?
  - ★ How to provide ongoing training for museum art docents and also facility activity directors
  - ★ Attracting folks with young onset Alzheimer’s to participate in socializing /activities
  - ★ How can we make mini-museums to send out to centers when museum space is not adequate
- 
- Is this about preparing museum educators for these types of experiences?
  - Art Museum Gallery Educator
  - Art Therapist
  - These two are different and neither needs to accomplish anything specific to the other – they are two different animals
  - Museums have restrictions
    - ~ Not enough staff

- ~ Not enough chairs
- ~ Not enough space
- What about bringing the art to the facility?
  - ~ It does work (per Maureen)
  - ~ Use 6-7 pieces of artwork
  - ~ On easels
  - ~ Positive is that by doing this you transform their 'home'
  - ~ And they have a memory in the facility
  - ~ Staff reacts positively
- Provide person (people who bring senior care residents to museums with information on art so they can continue the discussion back at the facility or create an art project)

### **Big Theme: Cultural Change/Public Awareness**

- International network (interdisciplinary)
  - \*Blogs – \*Google Group - \*Facebook
- Theme/Title
  - ~ Not seclusive
  - ~ "Alzheimer's Summit"
  - ~ "Virtual Summit"
- Marketing
  - ~ Community
  - ~ Persons with disabilities
  - ~ Funders
  - ~ Caregivers
- Stigmas
  - ~ With, not for
    - Training in Alzheimer's
- Language/Vocabulary
  - ~ Invite persons with dementia to write/contribute
  - ~ PERSON LIVING WITH Alzheimer's or Dementia NOT Alzheimer's People
  - ~ Evidence base/statistics
    - Buy-ins
    - Caregiver benefit

### **Big Theme: Art, Public Programs & Community Engagement (Outside of Museums)**

#### **Sub-themes:**

- ★ What are the common (specific) objectives and interests
- ★ Creating cultural change through public events
- ★ Communicating with similar programs, sharing of information

- ★ How do institutions extend the experience so that it becomes a more integral part of a participant's life?
- ★ How can our society be less segmented, more intergenerational?
- ★ Creating public programs based on Alzheimer's program success
- ★ Taking our learning to reach a broader audience for people living with disabilities and beyond Alzheimer's Disease

## **Big Theme: Art in a Changing Time**

- Dublin Contemporary Art Festival, Sept/Oct 2011:
  - ~ Temporary museum for 2 months
  - ~ Art options for people with disabilities
  - ~ Alzheimer's Society of Ireland is involved
- Weekly classes in art making in Atlanta, GA for individuals living at home –
- art experience accessible programming at festival for all disabilities, outdoor and indoor facilities housing festival
- “Outsider Art” – modern art museum in Dublin?
- May – art festival for older adults
- Public performance – Alzheimer's poetry day
  - ~ Create poems with residence in LTC facilities – ending with performance
  - ~ Caller response
  - ~ Triggering implicit memory
- Theme programming every two years at art institute
- Programs for those with Alzheimer's has influenced the rest of the programming... results in increased participation
- Designing programs that are inclusive rather than exclusive
- Just remove physical barriers
- Contemporary work – encourage new audiences
- Finding accessible points of entry... especially important for care partners.
- Visit care centers before Festival--- to insure participation, set up, transportation etc.