

***INVOLVING CONSUMERS IN STATE COALITIONS and the
CULTURE CHANGE MOVEMENT***
September 25, 2008

1. Who is involving “consumers” in their culture change activities?

Arlene Germain, president and co-founder of the MA Advocates for Nursing Home Reform (MANHR – www.manhr.org). MANHR is a member of the MA Culture Change coalition. MANHR is the sole statewide consumer advocacy group networking family councils and citizen advocates. They are an all volunteer organization working to improve the quality of care for MA nursing home residents. Arlene and Peggy McDonough, another MANHR co-founder, attended the coalition pre-conference.

Milissa Lake-Spencer from Indiana.

Peggy Moody from Arkansas.

2. Who has “consumers” on their advisory groups, in their Culture Change Coalitions?
3. How many of you have seen the new PN video?
4. Have any of you used the video?
5. There is a mini-website for consumers ~ with a listing of questions to ask when looking for a “culture changed” nursing home... NOTE that this is for NURSING HOMES... not the whole continuum of care...
6. The Pioneer Network is expanding the scope to all aging services environments: Home Care, Adult Day Services; Aging Network Agencies (e.g., Area Agencies on Aging and their contract providers); Assisted Living; Hospice; Hospitals; PACE programs; Rehabilitation/ Post-Acute Services; Retirement Communities; Senior Centers; Senior Housing; Wellness Centers; Nursing Homes; and disability-related organizations.
7. I suggest that WE HAVE TO REACH CONSUMERS/FAMILY BEFORE THEY ARE IN NURSING HOMES. We have to reach them early in the caregiving process, before they are totally in crisis looking for an “available nursing home bed” when they have to get out of the hospital within 24 hours...



**There is no
preparation time for
becoming a
Caregiver...**

People become Caregivers at a time of crisis...

When they get "THE PHONE CALL."

They aren't "shopping" for your services until they are in crisis.

Many don't yet realize that they are Caregivers...

SOS





In Crisis, Caregivers don't even know what they need!

Help them define it.

Give them the solutions in a language that they understand.

Don't talk in acronyms (the "ABCs" of long-term care)

You can't assume that they know *anything* about long-term care.

Look at your organization through the eyes of your consumer...



**LOOK AT
EVERYTHING YOU
DO THROUGH THE
EYES OF YOUR
CONSUMERS.**

"Find out what's on their minds first: it's important to them."

- Jack Falvey

"You must look *into* people, as well as at them."

- Lord Chesterfield

8. Letting all aging services providers know about the Culture Change Movement so that they are aware that consumers are going to ASK and DEMAND these “services” and “culture changed care.”
9. Letting all consumers (Elders, Family Caregivers, Loved Ones) know WHAT TO LOOK FOR and HOW TO “SHOP” for aging services.
10. AAHSA focuses on the entire aging services continuum. They focus on the ELDER and what’s good for the Elders ~ not on the providers... Other associations focus on the PROVIDERS more than the ELDERS themselves... See the AAHSA guiding principles (attached).
11. AARP
12. Ombudsmen
13. CoAge
14. NCCNHR
15. Centers for Positive Aging
16. Churches/etc...
17. Civic Organizations (Rotary, Jr League)
18. Chambers of Commerce
19. Alzheimer’s Association/Disease Organizations
20. Doctors/Hospitals – Where People Get THE DIAGNOSIS/become caregivers...

**WHO ARE THESE BABY BOOMERS?
78.2 MILLION STRONG**

**Post-World War II, 92% of GIs who came back from the war
got married. 84% had children ~ MANY CHILDREN.**

Born between 1946 and 1965.

Hence the BABY BOOM generation.

Baby Boomers and Their Parents, George P. Moschis, PhD

THE WORLD WAR II GENERATION

Born between 1936 and 1945.

Currently entering the 65+ category.

(1 in 6 Americans will be over 65 in 2025.)

The Brookings Institution, Living Cities Census Series, May 2007

THE “OLDEST OLD”

The 85+ population has grown 274% between 1960-1994.

There are 4,859,631 85+ in the U.S.

18.2% of 85+ pop. live in a nursing home.

770,000 of 1.6M NH residents are 85+.

36% of 85+ live alone.

50% of 85+ will have dementia.

CAREGIVING

**71% of Boomers (41 – 59) have at least one living parent.
29% have no parents living.**

**79% of Younger Boomers (41 – 50) have at least one parent living.
21% have no parents living.**

**41% of Older Boomers (51 – 59) have at least one parent living.
59% have no parents living.**

35% of Boomers are – or have been – responsible for their parents' care.

34M Americans provide some care for a family member age 50+.

In 2008, 54% of the work force will be involved in caring for an older person.

The majority of Caregivers are middle-aged (35 – 64 years old).

The typical Caregiver is a 46-year-old woman who works, has at least some college education, and cares for her 75-year-old widowed mother who lives nearby.

Of those caring for someone 50+, the average age of Family Caregivers is 47.

The average length of Caregiving is 4.3 years.

Nearly 4 in 10 Caregivers are men.

**96% of Caregivers influence purchase decisions.
79% purchase all or nearly all Caregiving products.**

The internet is the #1 place Caregivers turn to for information on Caregiving (29%), followed by doctors (28%), and 10% turn to nurse or other healthcare professional.

56% of all Boomers think it's a family responsibility to have elderly parent living in adult child's home. But just 38% of adults 60+ think this is a responsibility... Older either prefer their autonomy or perhaps don't want to be seen as a burden.

Even though most Boomers see it as a responsibility to house an elderly parent, not many actually do so. Among all adults with at least one living parent, just 14% have a parent living in their household, and among Boomers with a living parent just 8% do so.

20% of Boomers report that parent or parents reside in an assisted living or other facility...

85% have talked with their parents about their parent's health.

53% have talked about their parents living arrangements.

Women are more likely than men to talk about these subjects with a parent.

Most Boomer women have had conversations with their parents about their ability to live independently as they get older, but less than half have actually begun planning for care their parents might need. Results from this survey of women age 45+ suggest that significant opportunities exist for educating the public in this area.

69% have had conversations with their parents about their ability to live independently as they get older. However, only 40% have begun to plan with their parents for assistance they may need in the years to come.

In considering where their parents might go if they were unable to live by themselves, respondents most often mentioned having their parents move in with them (43%) or remain at home with paid help (33%). Only 17% had considered the possibility of their parents moving into a nursing home.

The majority are familiar with community resources their parents might draw on, such as assisted transportation, meal services, adult day care, assistance with everyday activities, and assisted living facilities. (Kim thinks that they don't know how to even begin looking or "shopping" for these services!!!)

More than half of respondents have begun to think about their own ability to live independently when they get older and how they would pay for any assistance they may need.

SANDWICH GENERATION

42M American women between the ages of 35 and 54 who are "sandwiched" by the needs of their children and their aging parents.

"Club Sandwich" are taking care of grandchildren and grandparents.

Average person in U.S. spends 17.5 yrs caring for their children, AND 18.5 yrs caring for an aging relative.

ALZHEIMER'S/DEMENTIA

Every 71 seconds, someone in America develops Alzheimer's disease.

5.2M Americans have Alzheimer's disease.

8.9M American Caregivers care for someone 50+ who has dementia.

10M U.S. Baby Boomers will develop Alzheimer's disease.

1 in 3 Americans knows someone with Alzheimer's disease.

1 in 10 Americans has a family member with the disease.

1 in 8 persons age 65+ has Alzheimer's.

Half of all nursing home residents have Alzheimer's disease or related dementia.

Only 63% of older nursing home residents have children, compared to 81% of older people in the community.

- GHCA

Women are more likely than men of comparable ages to enter a nursing home. The lifetime risk of being in a nursing home for women at age 65 has been estimated at 52% and that for men at 30%.

- GHCA

Nearly 84% of nursing home residents are without a spouse, as compared to 45% of the living-at-home elderly.

- GHCA

ASSUMPTIONS
about “CONSUMERS” and LONG-TERM CARE
by Kim McRae early 2007

People usually become a “caregiver” during a crisis – following a death of a spouse who was the primary caregiver or a hospitalization (someone has a stroke, breaks a hip, etc), or perhaps after a visit home when they see “the state” that Mom or Dad are in...

They usually have to make a decision about nursing home placement VERY QUICKLY
 (“Oh My God! The hospital says we have to get out in 2 days! Where do I put Mom?!”)

People in the “beginning stages of caregiving” know VERY LITTLE about ANYTHING about long term care ~ they don’t even know the definitions of the different long term care options
 (What’s the difference between a nursing home, a rehab facility, assisted living, assisted living with Alzheimer’s care, continuing care facility, in-home care options, etc)

The world of long term care and the aging and community services “world” is very complex and disjointed – it’s tough to navigate... What is the AAA? They are supposed to help. Why would I need a “social worker” (people think social workers are to care for orphan children, for example). What is an ombudsman? (many people have never heard of this term). People don’t know what a QIO is or what their role is... Much less, each state is different and the rules and regulations and services vary greatly... Especially confusing if someone is a long-distance caregiver... There are so many different agencies and branches that do different things that it’s hard to understand who does what... (Much less when you try to figure out county versus state versus federal services!)

Aside from all of this, ***HOW AM I GOING TO PAY FOR ALL OF THIS?!?!?***

This becomes the main focus – in addition to having to find something FAST
 People don’t have a clue how all of this works...
 AND THEY ARE FREAKING OUT AND IN A PANIC

From an AARP Report on Perceptions and Realities about Long-Term Care:
(quoted in an article, “What we don’t know about long-term care”, Humberto and Georgina Cruz, Tribune Media Services, January 23, 2007)

A “substantial proportion” (45 and older) apparently believes they have long-term care insurance when they don’t.

“In general, Americans 45-plus do not know what long-term care services cost and do not know about coverage,” said the report, prepared by the research firm GIKNOP Roper Public Affairs & Media.

They were told that long-term care means care provided on a regular basis for three months or more for age-related or other chronic conditions.

Only 8 percent of Americans today, compared with 15 percent in 2001, could come up with an estimate within 20 percent of the average cost of a stay in a nursing home.

That cost is about \$6,266 a month, based on AARP calculations... Almost two-thirds, or 63 percent, thought the cost was lower, and 17 percent admitted they didn’t know.

Just 23 percent could come up with an estimate within 20 percent of the average cost of an assisted living facility, which is about \$2,968 month.
More worrisome, 59 percent mistakenly thought that Medicare covers nursing home stays of three months or more for age-related or chronic conditions.
52 percent of the people believed that Medicare covers assisted living, compared to 41 percent who did in 2001. In fact, neither Medicare nor any private Medigap policy covers the cost of assisted living in any state.

“Americans 45-plus know less about long-term care than they think – and that they should. Given the high and accelerating costs associated with long-term care and the growth of our older population, it is critical Americans become more informed about the costs, funding sources, coverage options, and state and community resources.”

All of that being said...

Once they have figured out about Medicare, VA benefits (which can take forever to get), Medicaid and how to qualify (if it's even possible with look back periods, spend downs, etc)...

And once they have gotten all of the forms filled out and the medicine regime figured out

And once they have found a place that has an opening (a **BED**)

And once they have found a place that doesn't smell like urine, is relatively close geographically, is a place that they can tolerate based on the best decision-making that they can make based on what they've learned in a short period of time...

The loved one is placed...

Then comes the time when they can really start figuring out is they've made the best decision...

This is when they'll start really getting into figuring out and worrying about “the home” where they have placed their loved one

This is when the guilt is really kicking in and they start thinking about the kinds of things that we want them to focus on ~ person-directed care, self-determination, etc...

I challenge us to push for creating and using LONG-TERM CARE language as opposed to just using NURSING HOME language...

If we can get these “consumers” to start thinking about these things EARLIER – before they are forced to make snap quick decisions – then they will have an opportunity to be better “shoppers” and to really know what they need to be looking for...

Unless it's an emergency (after a hospitalization or major health crisis), the first things that people have to look into is in-home care, adult day care, assisted living... The goal is to help them *phase into nursing home placement...*

We've got 2 scenarios regarding the family caregivers:

1/ Those that are already in a nursing home ~ does their home have these values? If not, do they need to look for another facility and perhaps MOVE their loved one? If their home does not have these values, how to introduce their home to these values and get the home to “get on board” without causing the family caregiver to piss off the home (which they fear will cause the home to be mean to their loved one)

2/ Those that are in the process of “phasing into long-term care” ~ they are somewhere in the spectrum of figuring it out and choosing how to use it... How to teach them how they can look for these values within every “level” of long-term care... Something else that is very important to remember:

What if “THERE’S NO PLACE LIKE HOME!!!”

That’s the situation that I’m in - - I’m a family caregiver that WANTS “THIS” and it does not exist here in Atlanta... This makes me frustrated and guilty ~ I am not getting the best care for my mother! I’ve got Mom in a place that’s INFERIOR... What can I do?!? I try to talk about this to others and the assisted living home itself...

The big question that we have to answer is:

**HOW MUCH DOES THIS COST?
THIS HAS TO COST MORE THAN “THE WAY IT IS!”
THIS IS FANTASY WORLD!
I CAN’T EVEN AFFORD WHAT I’m PAYING NOW!**

WE MUST PROVE THE BUSINESS CASE – for families AND professionals

As I’ve said, we need to assume that CONSUMER = CULTURE CHANGE VIRGIN
Someone who has never heard about “this” before
Be it a “professional” or a family caregiver

Everyone has a parent ~ or is going to be directly touched by having someone that they love AND THEMSELVES ~ growing older and/or dependent on the care of others...

This has to be “Culture Change 101” for whoever sees it ~ and we want EVERYONE TO SEE IT

As we’ve already said, to the uninitiated, the phrase CULTURE CHANGE turns them off...
So we need to talk about PERSON-DIRECTED CARE and WHAT THAT MEANS with very specific examples

“You never really understand a person until you consider things from his point of view . . . until you climb into his skin and walk around in it.”

**Atticus Finch
To Kill A Mockingbird**

Let’s climb into the skin of the “consumers” and walk around in it...

Let’s not forget that everyone is going to get old...

Let’s not forget that everyone has a parent...

Let’s not forget that family caregivers feel SO GUILTY that we don’t want to make it worse

Let’s not forget that the language of the “professional” is NOT the language of the “virgin”

Let’s not forget that all universal religions teach THE GOLDEN RULE
~it’s about DOING UNTO OTHERS