

## ADRC Streamlining and Access Focus Groups

### Introduction

Five focus groups were held throughout the Island of Oahu. It was determined that each focus group should be relatively homogeneous in make-up in order to maximize the potential for shared experiences. An effort was made to have reasonable representation of varying genders, ages and ethnicities and this diversity is reflected in the responses. The following categories of groups were run:

- Active Seniors
- Caregivers
- Underserved minority group (seniors and caregivers)
- Younger adults with Physical Disabilities
- Long Term Care Service Providers

Total Number of Participants: 49

Average Group Size: 3- 12

Timeframe of Focus Group Interviews: January - June 2007

Sites: Various throughout Honolulu, Hawaii

### Methods

The script was developed by Wesley Lum and was modified and pre-tested with the assistance of students in a sociology Ph.D. seminar on survey research. Each group was asked the same questions in the same order, although prompts and probes varied by group. Each session lasted from an hour to an hour and a half and was conducted at a site that was familiar to the participants. Each focus group had one facilitator from the executive office on aging and at least one recorder. With the permission of the participants, Ph.D. students from the University of Hawai'i were allowed to observe and assist as part of their learning experience. The sessions were also audiotaped. The data were analyzed using a combination of recordings and notes. Due to audio difficulties some recordings were not possible to use and notes only were used.

### Summary of Findings

#### Question 1 (Self introduction; sharing of caregiving experience)

1. Those who mentioned who they were caring for said:  
*(Nearly all were caring for a family member or relative.)*

- Husband (4 times) girlfriend's husband (once)
- Wife mentioned twice
- Dad/ father mentioned six times; one father-in-law
- Four people mentioned mother; one mother –in-law

- Two people mentioned in-laws as a couple
- Three people mentioned caring for both aged parents; one for a husband and wife together where the relationship to the caregiver was not established
- One person mentioned aunt
- Two mentioned sister
- Two people mentioned son or grandson
- Several were professionals/ professional volunteers in addition to their own personal caregiving experience

**2. Among those who mentioned a reason for care, the following was said:**

*(Reasons—age and health. Unclear whether need is for a short duration or long-term/permanent—at least one (sprained shoulder) appears to be short-term.)*

- Elderly
- Stroke (mentioned twice)
- Lung cancer
- Dementia
- Disability
- Sprained shoulder,
- Cannot be left alone
- Heart problems
- Blindness
- MS

**3. Among those who mentioned the type of care they provide, the following was said:**

*(Two broad categories of care—direct and indirect.)*

***Direct:***

- General assistance with ADL's,
- Assistance with dressing
- Assistance with transportation
- Exercise needs
- Companionship for a person who lives alone
- Making /getting to appointments

***Indirect:***

- Managing care
- Hiring help
- Getting information on /applying for needed benefits
- Several participants discussed the fact that their care recipient had already been institutionalized in a group home or nursing home and that they had handled the placement

Other themes not in direct response to question reflected:

***(Direct)***

- Length of care
- Multiple caregiving experiences
- The burden of care (financial, physical)
- Inability to provide 24 hr care as reason for institutionalization
- Personal exhaustion

***(Indirect)***

- Confusion about finding resources to help
- Hard to find personal care attendants.
- Affordable housing is a big issue
- Doctors have been helpful.
- Family support crucial

**Question 2 (When did you realize that you had become a caregiver (or became disabled yourself) how did you access help? Who did you turn to for information? Any negative experiences?)**

***(Medical/Service Provider)***

- Hospital social worker or discharge planner/ case managers
- Doctors
- In-patient case manager
- Foster care home/other care homes

***(Family/Friends)***

- Friend
- Family/especially health care professionals in family

***(Community Agencies)***

- Salvation Army
- Service organizations
- American lung Association
- KKV (Kokua Kalihi Valley?)
- HGP

***(Emergency contacts)***

- Lifeline
- Called 911

***(Government—Third party payors)***

- VA/military
- Social security SSI
- Medicaid /DOH

***(Information/Resources)***

- Got senior handbook
- Caregiver conferences
- Websites/Internet
- Called 211
- 211 online services.
- Media (newspaper, TV ads)

**Negative experiences mentioned many times no matter which system was accessed for help. Among the comments were:**

***(Medical/Service Providers)***

- Social workers/ discharge planner and case managers left a great deal on the caregiver to figure out/ find out
- Only time you receive services is during hospital discharges; otherwise on your own
- Private case managers? Too expensive
- Raised issues of confidentiality and not honoring of powers of attorney by many caregivers who were seeking benefits/ eligibility establishment for a care recipient

***(Community agencies)***

- Service organizations were too paperwork oriented, not client oriented enough

***(Government—Third party payors)***

- VA benefit process was confusing; conflicted in the end with SSI benefits some of which then had to be returned
- Medicaid was mentioned at least twice as being very busy
- Insurance ‘hard to get for younger people who are non medicaid eligible and doesn’t cover personal care anyway

***(Information/Resources)***

- Had to call many times; referred around; hard to find time to follow-up if employed
- “Kept hitting my head against the wall”
- Bad experience with 211 phone line

**Questions 3-5 (on phone number vs website vs physical site)**

**Phone comments:**

***Desirable Features***

***(Human contact)***

- Want a live person
- Don’t want phone menus
- Seniors may have problems calling: selecting numbers, menu (confusing), want to talk to person
- Don’t want to get answering machine

***(Accessible)***

- Must speak my language
- Should be 24 hours
- Should be a toll free number
- Number should be well advertised on the media at time when seniors watch on channels they watch
- Don’t want to be put on hold.

***(Helpful)***

- Don’t want to be denied information ( confidentiality issues)
- Want to talk to a person who is very knowledgeable

- Need person to person help; what about help completing forms?

### **Website comments**

#### ***(Concerns)***

##### ***(a. Not for elderly)***

- Might be ok for younger people
- Would be good for younger caregivers
- Website is good for younger family members.

##### ***(b. Access)***

- Not everyone has computers
- Must be easy to navigate.
- Again, what about language problems?

##### ***(c. Other)***

- Should be like one stop shopping, only on line

#### ***(Benefits)***

- Has lots of information access with useful information.
- More likely to have current information and all available information.
- Also alternatives. Example was choices of case managers, and care homes
- All people would use website (comment from MS group)
- Have FAQ's; Q and A; links to other websites
- Have wi-fi at the ADRC.

### **One stop physical site comments**

#### ***(Benefits)***

- Faster service. One building would be convenient for workers (employed caregivers?).
- If need care and help, you can't be running around. Getting confused.
- Good place for an education center.
- Would go if I knew I could get help there
- Good for person to person help
- Especially needed for Medicaid /forms

#### ***(Concerns)***

##### ***(a. Access)***

- Buses would help/transportation is needed
- Needs eves and weekends for working people
- Waiting is an issue.
- Would be good but what about waiting time?
- So many people in need, walk-in site would be overbooked. Will need to schedule an appointment.

##### ***(b. Client Oriented)***

- Want it to be customer relations oriented, not like social security
- Structure/physical facility with a person held accountable would be good.
- Want people to speak my language /dialect and know about my culture there
- Tracking system for clients

**(c. Concerns)**

- Precaution of one-stop resource: may break down existing line of communication between agencies
- Don't want building. Save \$\$\$. Put resources in people

**How could services be improved?**

- Consolidate services for younger people with disabilities..
- Like Social Security, have \$\$ come out of paycheck to pay for the future.

**Final Questions: (Type of publicity? Name? Logo? Further comments?)**

**Publicity methods**

- Publicity/ information should be disseminated thru sites where seniors go
- Videos in doctor's offices
- Documentary for Sundays (reporter ½ hour?).
- Morning news, specific time or on evening news. Many caregivers leave for work early.
- Classes/meetings/ other face to face opportunities
- Training professionals on info to give to others

**Names**

- Some appreciation of 'first call' and 'senior care link' names
  - Discussion of inclusive nature of name
- Some suggestions (I didn't know which) had negative connotation suggest mental health?
- Another reminded people of Kahi mohala (Kahi Malama?)
- Hawaiian names seen as possibly only serving Hawaiians
- On first call - someone said it reminded them of Bank of Hawaii
- Name shouldn't be an abbreviation or too long
- Shouldn't sound like any existing agency

Other suggestions included:

**(a. Service population)**

- Aging and Disability – all ages included
- Elderly Community (can add younger people later)

**(b. Service)**

- First Call for Information
- Caregiver Link
- Resource Hawaii

**(c. Both Service and Service Population)**

- Senior Care Link Hawaii.
- Hawaii Aging and Disability Information Resource Center
- Community Elderly Resource Center
- Community Resource Center for Elderly and Disabled

### **Logo suggestions:**

Lots of suggestions involving hands:

- Helping hands
- Pointing/joining hands (helping hands)
- Shaking hands with elder
- Welcoming/extending hands
- Helping hands like food bank.

Other

- Angel (guardian angel).
- Petroglif
- Elderly pushing wheelchair and disabled son through park
- Golden retriever
- Cane/wheelchair

### **Conclusions**

Several overall conclusions emerged from this analysis.

- (1) There is a need for consolidation and organization of information on long term care. People rely on a variety of methods to get information – from family to health care professionals to the media – without any rhyme or reason. There is absolutely no guarantee that any two people will get the same answer to the same question.
- (2) Negative experiences with the system far outweigh positive ones.
- (3) Younger disabled adults have different needs than elders and their families. Insurance availability and coverage, affordable and accessible housing, help finding personal care attendants, employment conflicts - are big issues.
- (4) While younger caregivers and younger disabled adults will use the internet and websites older adult will be less inclined to do so and would prefer a phone line, but only one answered by a human being without menus and it needs to be available 24 hours a day.
- (5) A physical site should have arrangements for walk-ins.
- (6) The current ‘referral’ method is difficult for both the elderly and younger disabled adults, where minimal information is supplied and then they are on their own to get services. Preliminary calls to verify information and eligibility /appointments and perhaps even care arrangements should be made whenever possible by professional ‘brokers’ who know how to ‘work the system’.
- (7) In terms of phone vs physical site, vs website, a phone number was slightly preferred, although there were many stipulations about using it. A general feeling that a website would be good for younger (read: more sophisticated, educated)

caregivers and family members. This feeling among older adults and caregivers was reinforced by the responses of younger disabled adults who said ‘everyone’ would use a website. It was accurately perceived that websites would probably provide a broader range of current choices. A few people strongly supported a physical site where people would talk to them face to face and be accountable for the results. These often sounded like people who had been frequently passed from place to place for information or help; however there were concerns about too many people using it and waiting time. There was a strong preference that a place like this should be ‘walk-in’ without appointments necessarily required.