

# **Blueprint for Aging**

**Family Caregiver Support Workgroup  
Final Report  
October 2005**

**Focus Group and Survey  
Results, Themes and Selected Comments**



## I. General Overview:

- Twelve focus groups were held between May and August 2005. These groups sought input on the experience of being a family caregiver, caregivers' current and emergent needs and their ideas for an "ideal" support system for family caregivers. Approximately 117 individuals participated in these focus groups. Most participants were family members of care recipients, with two groups being people who were in professional roles related to caregiving *and* were themselves family caregivers.
- In addition, a total of 97 individuals completed a survey questionnaire having 15 total inquiries, 13 of which were forced choices, 1 asked that a grid related to services be filled in and the last being an open-ended solicitation for comments on past and present services that the respondent considered to be most helpful. A database was created to organize and quantify the various responses to the questionnaire. A blank questionnaire can be seen as Attachment A.
- A Town Hall Meeting was held in Chelsea on June 22, 2005, during which there was a "Family Caregiver Support Breakout Session." Approximately 20 people participated. An overview of the results of this breakout session can be found on Page 7 of this report.
- 145 participants of the Retired and Senior Volunteer Program (RSVP) completed a survey that asked respondents to use a five-point scale to prioritize five areas of community services. In addition, these RSVP respondents were asked to add other types of community services not among the first five offered in the survey. Finally, the survey asked respondents where they imagined they would be living in the next 5 – 10 years and what kind of help, if any, they thought they would need to be able to remain in the living situation they identified in the prior question.
- In July 2005, 12 professionals serving family caregivers and their families were asked via a telephone survey to list their perceptions of the kinds of services needed to address four areas of concern regarding the continuum of care for older adults and support for their caregivers.
- On August 26, 2005, a telephone survey of area respite service providers was completed. This short telephone interview was to determine cost and capacity information from both non-profit and for profit respite service providers.

## II. Focus Groups - Overview of Results:

Twelve focus groups were held in numerous venues throughout Washtenaw County in order to obtain input from different geographical areas and from a cross section of the community of family caregivers. Caregivers were generally either a spouse or an adult child, usually middle-aged, providing caregiving to a parent (sometimes both, simultaneously or serially). A few participants were caregivers of a minor aged and/or disabled child but with concerns about their own aging and its impact on their ability to continue as caregivers.

### Six Areas of Focus Groups

Caregivers participating in the focus groups were asked to respond to six questions. The settings were informal and low key, with one person leading the conversation and another person writing key responses and issues on newsprint so that everyone could reflect on what had been stated. The specific wording of each question is on Attachment B.

More generally, the six areas for focus groups were:

1. Definition of a Caregiver
2. Positive Aspects (Satisfactions & Rewards) of being a Caregiver
3. Obstacles & Challenges of Caregiving
4. Turning Points/Time to Ask for Help
5. What Would Make Caregiving Easier?
6. What Would You Want in an Ideal World?

By reviewing the responses on newsprint across each of these six areas, certain themes tended to emerge. These themes, taken together, begin to paint a picture of how caregivers view their role(s) as caregivers in the larger context of their lives overall, what it is family caregiver's experience, how they came to understand they needed more assistance as caregivers (this was not universally the case) and what specific services, and more broadly, systems changes they thought would make family caregiving an easier to manage set of responsibilities.

There were no discernable differences in opinions expressed by focus group participants on the basis of race or area of the county in which respondents reside. The format of the focus groups was such that gender and other differences were not recorded, so that one must view ideas and opinions expressed in broad terms and resist any inclination to see group differences where none (apparently) exist.

It is significant that most caregivers responding did not express resentment or a sense of being burdened by their care recipients. Rather, and this was strongly and consistently expressed, caregiving was seen as "a normal and expectable part of life."

While caregiving was not seen as something most people would seek or choose it was nevertheless a role people assumed out of love for and generosity toward another.

What follows is a summary of themes that emerged from responses to each of the 6 questions, and comments, most of which are paraphrases of what participants stated, along with some direct quotes.

#### Themes for “Definition”

- Overall agreement with the definition offered: *“A person related by birth, marriage, adoption or emotional ties who provides psychological, emotional, spiritual, and/or physical support.”*
- Provider, protector, decision-maker, ultimately responsible.

#### Comments for “Definition”

- “Sometimes the role comes on suddenly.”
- “It is complicated when there is more than one caregiver. We don’t always agree.”
- Caregiving is, “An accumulation of all the little things that need to be done.”
- Families need to be educated on how much ‘clout’ they have, what their rights are in terms of decision-making for a loved one, and if they can make their own decisions or have to follow the recommendations of professionals, such as social service staff in hospitals.

#### Themes for Positive Aspects of Caregiving

- Satisfaction with “doing the right thing.”
- Giving back to ones parent (who took care of me). Keeping a promise or honoring a commitment.
- Closer relationships with loved one and with other family members.
- Setting a good example for younger family members.
- Shared experiences. Love and laughter.
- Knowing that my loved one is being taken care of.

#### Comments for Positive Aspects of Caregiving

- “Knowing mom is safe, eating, getting medical care, attending church; it was harder to know these things when mom didn’t live with me.”
- Being able to look oneself in the mirror and face oneself after making each decision about a loved one helps; don’t make decisions when you are totally burned out.
- “Dealing with this, I was able to show my children that this is a normal part of life and that people do get through it.”

### Themes for Obstacles & Challenges

- Financial stressors: how to pay for respite (to get away for a while), extra supplies, food, etc.
- Distance Caregiving (adds significant additional challenges).
- No professionals see the “whole picture,” and the caregiver must patch together a series of supports and services.
- Dealing with difficult/unhelpful family members.
- Caring for a loved one with no help from other family members.
- Role reversal; parenting one’s parent. Accepting changes in family roles.
- The strains caregiving puts on other family responsibilities and relationships.
- The challenge of knowing what is available.
- Having to fight for money (e.g. insurance) and for services.
- Toileting and bathing (especially one’s parent).

### Comments for Obstacles and Challenges:

- “It would be easier and save time to just use a wheelchair instead of walking each day, but that’s not best for the person.”
- “I have to be the expert-schools and medical staff are not.”
- “You lose your (own) life.”
- “I’m my biggest obstacle. I have difficulty accepting change. I get angry and upset about little things.”
- “It was so daunting to go to the Alzheimer’s support group that I never went.”
- “Some family members don’t help at all. They’re oblivious.”

### Themes for Turning Point/Time to Ask for Help

- Constant feeling of being overwhelmed.
- Seeing that the loved one was deteriorating, that regular visits were not enough.
- Loved one had an accident.
- The caregiver became ill.

### Comments for Turning Point/Time to Ask for Help

- “I couldn’t manage it any more.”
- “When my husband fell and broke his foot, I became very anxious and had to go on medication myself. I realized I needed to reach out for help, and contacted a social worker.”
- “Watching my husband slowly decline, especially given his young age (67).”
- “The social worker was very good and saw that more help was needed.”

### Themes for What Would Make Caregiving Easier?

- Time for myself. Getting a break. Sleep.
- Completing one assessment that could be used by multiple agencies.
- Better communication within and among organizations.
- Having a case manager or someone who could see the big picture and coordinate all services.
- Having a network of support.
- Having home modifications and proper equipment at home.
- Financial assistance.

### Comments for What Would Make Caregiving Easier?

- “It would be nice for people to come forward and do things that are helpful and thoughtful. It’s difficult to ask for help.”
- “I could have used support after my mother died. I wonder if I could have done more, or if I caused her to get worse.”
- “If I had known what to expect early in the process, I would have been better prepared.”
- “Weekend respite was a big help.”
- “I just can’t handle it all day.”

### Themes for What Would You Want in an Ideal World?

- Comfort, Care, Compassion, Dignity and Respect.
- Respite services in the home and site based. Freedom.
- Meaningful things for the loved one to do. Addressing the loneliness of the care recipient.
- Long term care insurance. Affordable long term care.
- Affordable support services (to avoid or delay nursing home).
- Having a supportive family and friends.
- Affordable housing built with older adults in mind.
- Health care and other providers who communicate with each other.
- A system of care and support that allows the loved one to age in place.
- A caregiver support system.
- Transportation assistance.
- Knowing what to expect.

### Comments for What Would You Want in an Ideal World?

- “Doctors need to be more attentive to the stresses and needs of the caregiver.”
- “The way family caregivers gain information about and obtain assistance could be improved.”

- “Current respite services do not meet the need.”
- “There should be tax credits for caregivers who sacrifice their income (by not working and caring for a loved one.)”
- “I want to stay socially active with friends and family, and to be embraced by those around me.”

### **III. Town Hall Meeting:**

On June 22, 2005, a Town Hall Meeting sponsored by the Blueprint for Aging and Chelsea Community Hospital was held at Pierce Lake Elementary School in Chelsea, MI. Following a keynote address by a guest speaker, attendees were invited to participate in one of four breakout sessions, one of which dealt with the topic of Family Caregiving. Approximately twenty (20) individuals participated in the caregiving breakout session. The group represented an even mix between individuals and representatives from service agencies both non- and for-profit.

Participants were presented with lists of major issues and recommendations proposed in the Blueprint for Aging. Participants were then asked to react to this information and identify anything they felt was missing, offer their feedback and suggestions, propose new ideas, and finally to prioritize the information presented.

The items listed below in bold are those that were voted as being of high priority by participants. For a complete summary of the breakout session, see Attachment C.

#### Proposed Major Issues for Public Feedback

- Beneficial education and support programs reach a fraction of caregivers.
- The way family caregivers gain information about and obtain assistance could be improved.
- Family caregivers can benefit greatly from “respite” care that provides periodic relief from daily stresses.

#### Proposed Recommendations for Public Feedback

- Increased education for caregivers, physicians, employers, and the general public.
- Increase the amount of respite services and adult day programs in the county.

#### **Public feedback and reactions to proposed major issues and recommendations**

- **Educate physicians about issues faced by caregivers.**
- **Affordable senior housing with on-site services.**
- **Affordable respite care.**

#### **New Ideas Proposed by the Public**

- **Training and screening for respite care workers and home health aides.**
- **Someone to call and check in on a caregiver.**
- **Make caregiver mediation services more well known.**

#### **IV. Survey Questionnaire, Overview of Results:**

Of the 97 individuals completing the questionnaire, the most frequent age range was between 60-69 and 70-79, and the third from 80+.

Gender of responding caregivers is 75% female and 24% male. Marital status is 65% married, 16% widowed/widower, 14% single and 4% divorced. 77% of respondents are Caucasian, 16.5% African-American, 2% Native American and 3% Russian émigrés. Fully 66% of caregivers work full time outside the home, with another 19.5% working part time outside the home and 13% not working outside the home.

The geographical distribution was coded by zip code, with the modal number (26) from the Ypsilanti area, followed by 15 from Saline, 14 from Ann Arbor, 12 from Dexter and smaller numbers from 11 other zip codes.

The age of care recipient ranged from the modal 29 care recipients between ages 80-89, 19 between 70-79, 9 from 60-69, 2 from 50-59 and 11 below the age of 18 (with an aging caregiver). Missing data in this category was high at 19.

Relationship of the caregiver to the care recipient ranged from the modal response, spouse (30), to adult child (26), to grandparent (12) with lesser numbers for other relationships, primarily family.

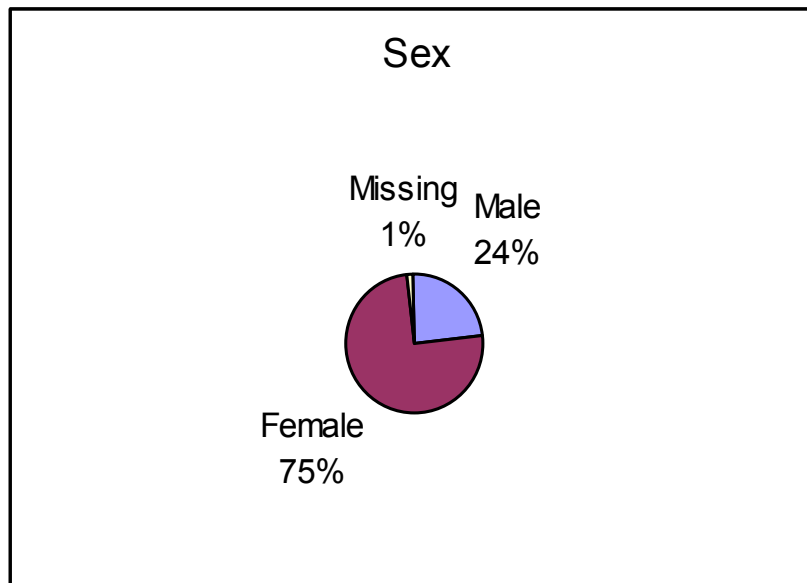
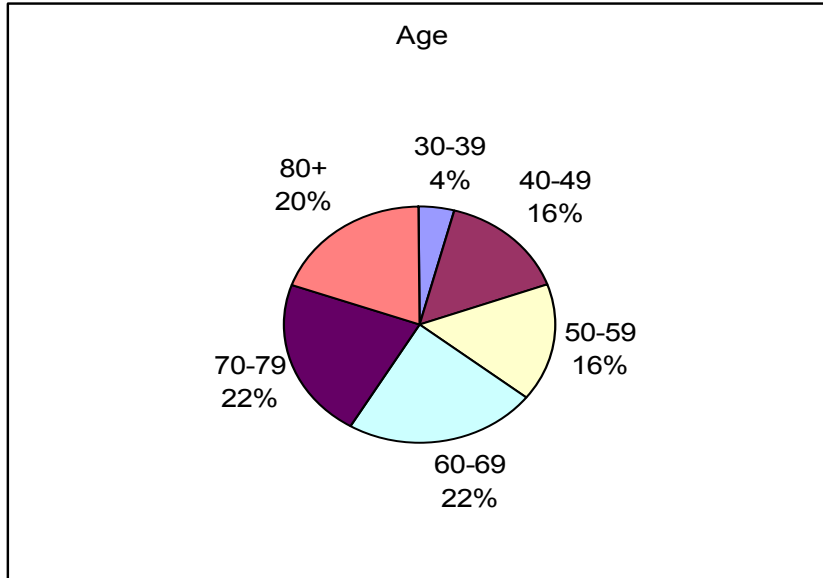
59% (57) of caregivers report that they are living with the care recipient, with 27% (27) reporting that they do not live with the care recipient. (There were 14 not reporting in this category).

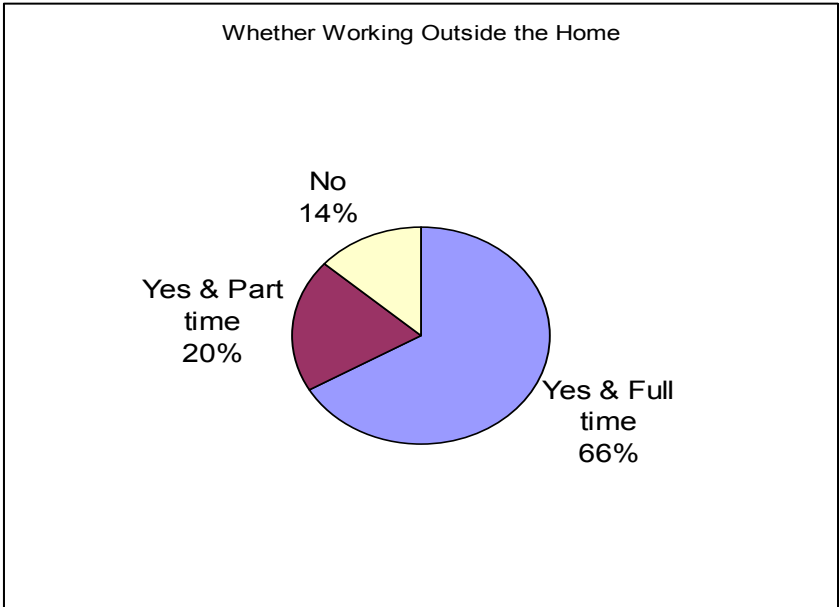
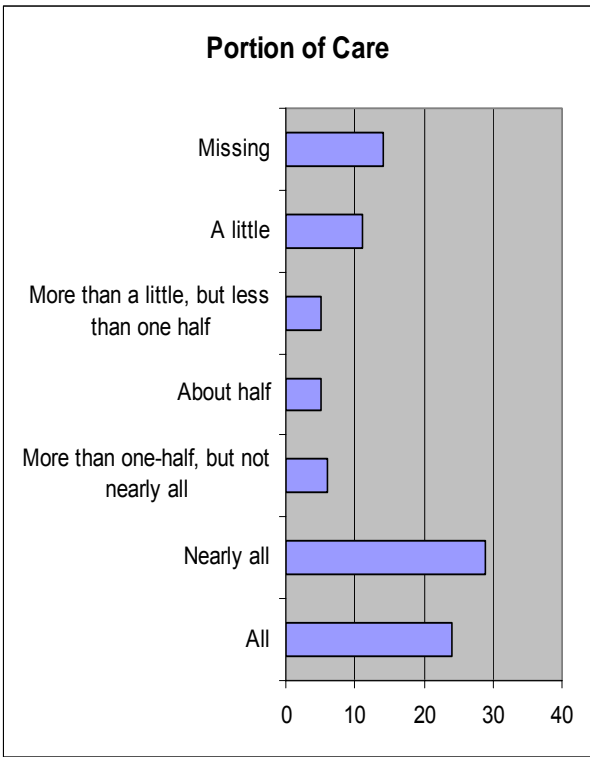
The period of care giving (in years) ranged from the most frequent, 20, reporting 6-10 years to 17 reporting less than 2 years. Six respondents reported caregiving between 10-15 years, 4 from 16-20 years and 3 greater than 20 years. More than half of respondents (55) reported that they provide caregiving on a daily basis. The number of hours of caregiving per week ranges, from 25 reporting 24 hour/ 7 days a week to 25 reporting between 6 to 40 hours a week, with 12 reporting less than 5 hours per week.

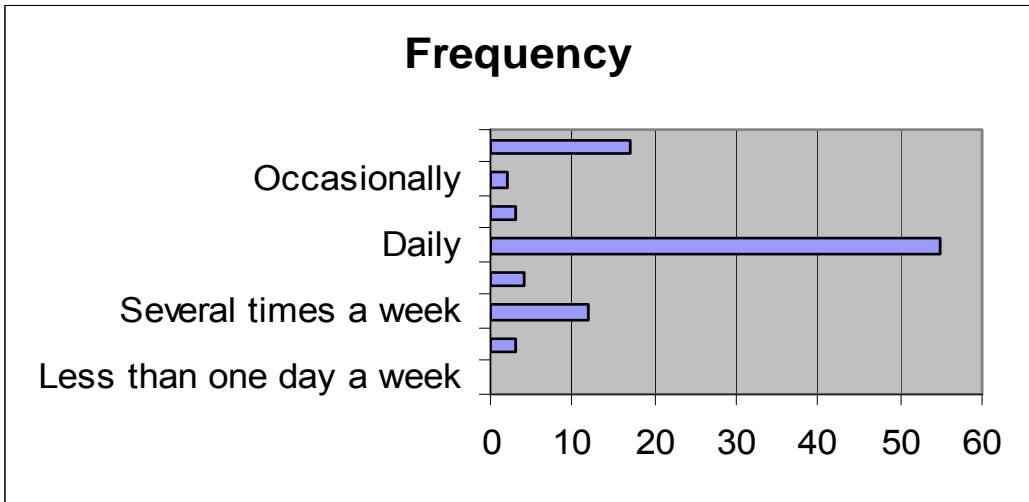
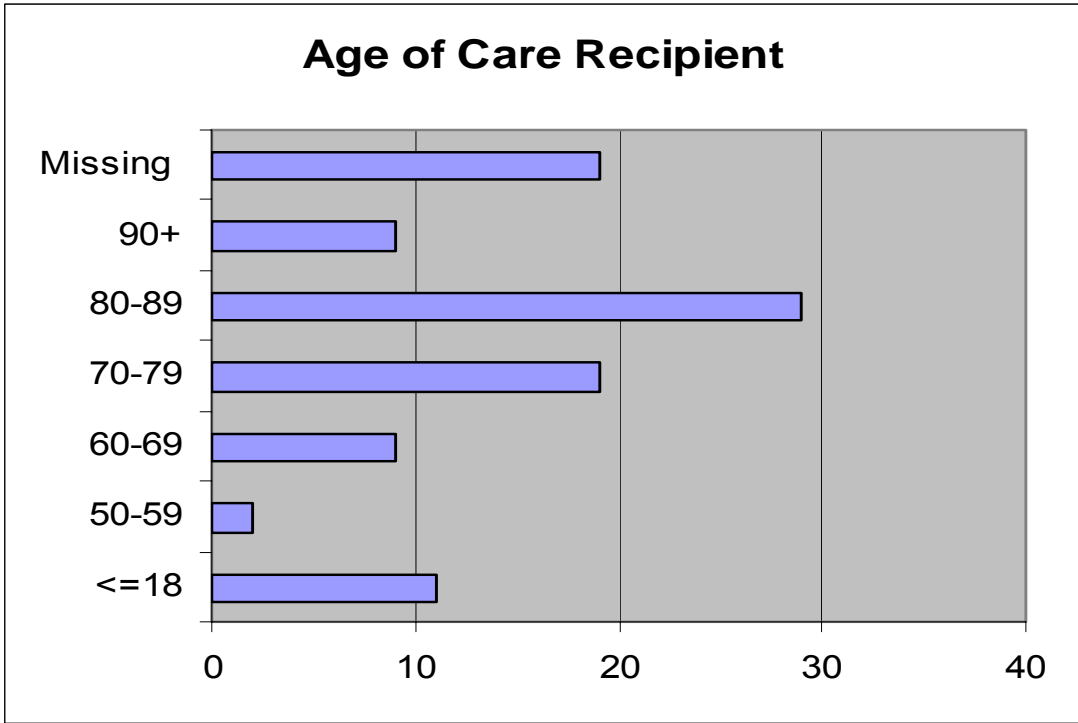
To the question asking how much unpaid caregiving the respondent provided, 24 reported they were the sole caregiver with another 29 reporting they provided “nearly all” care, meaning 55% of respondents report having no (unpaid) support from other family members or friends.

Question 14 was a four-column grid, asking respondents to indicate past or current use of any of 17 specific kinds of services that may provide support to caregivers. Using the grid respondents were asked to check off one or more columns for each of the 17 services, and to indicate whether they “ 1) Know of; 2) Have used; 3) Find Helpful and 4) Would Use.”

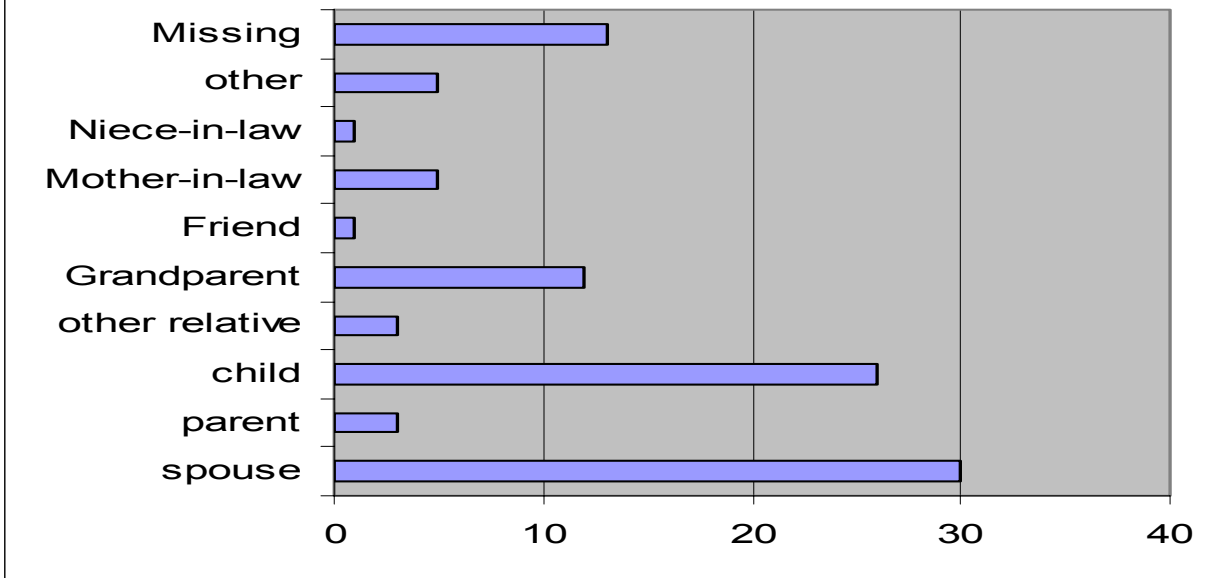
Responses to the grid are represented in graphic form on pages 14 – 16, as follows. Numbers on the bottom of each chart are percentages.



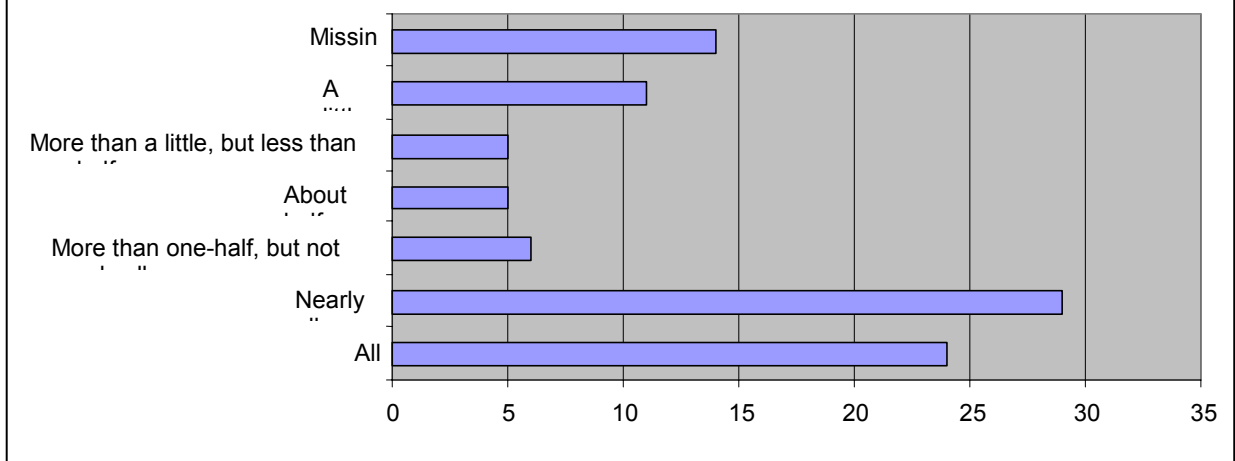


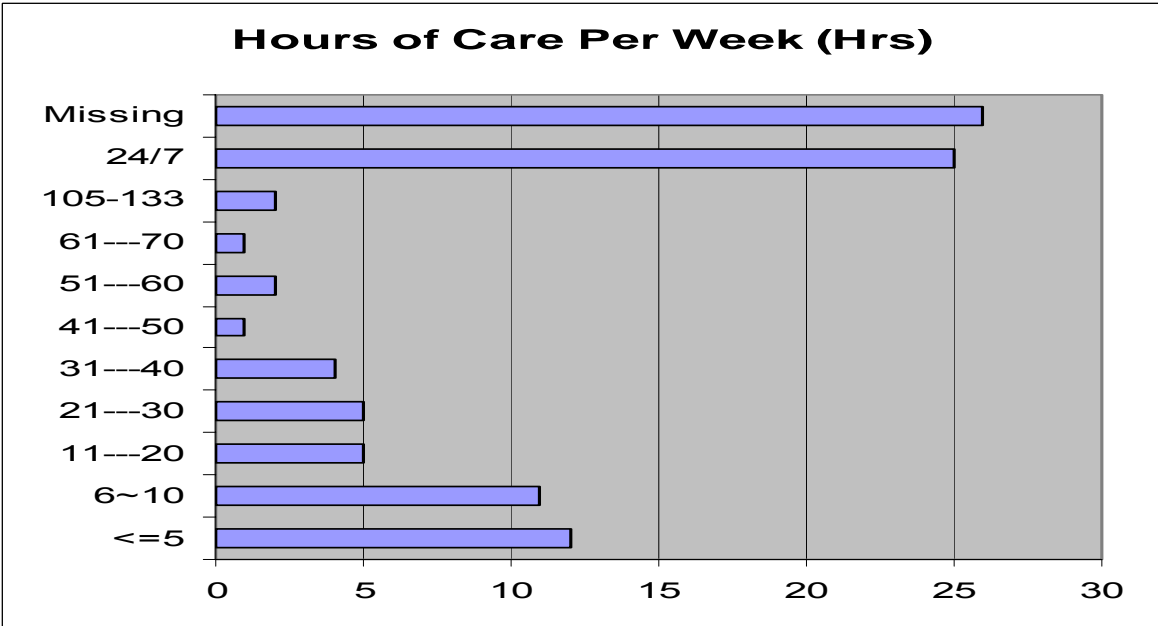
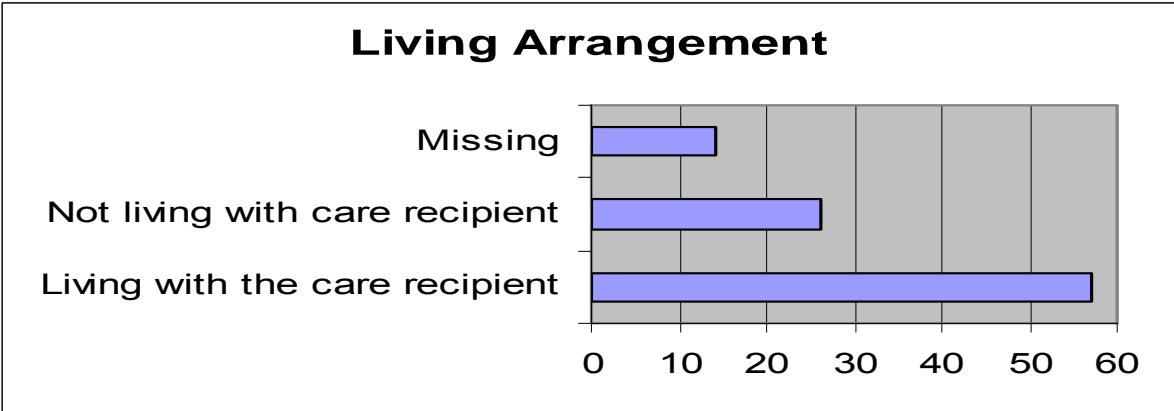
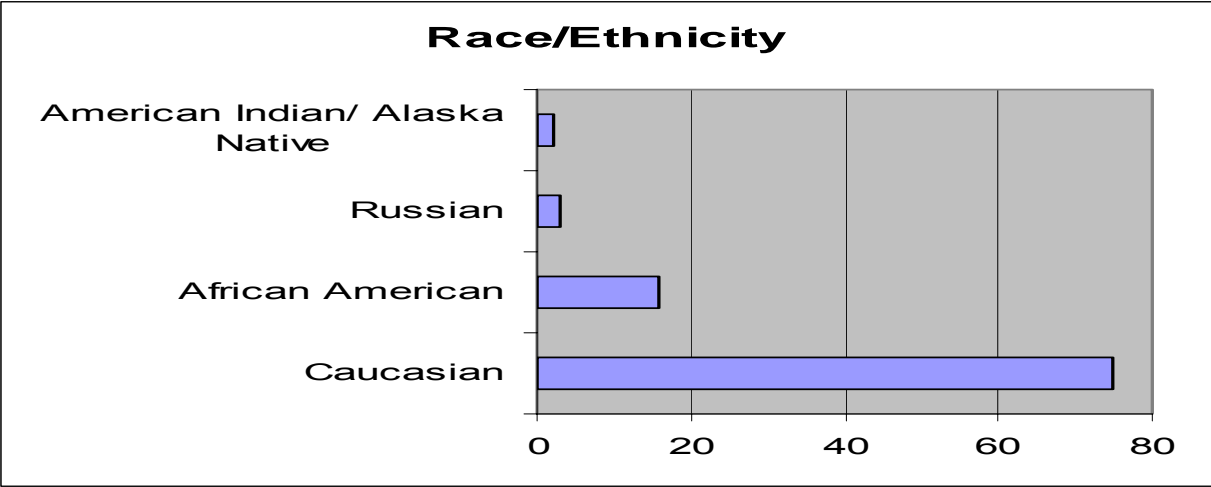


## Relationship of Care Recipient to Caregiver

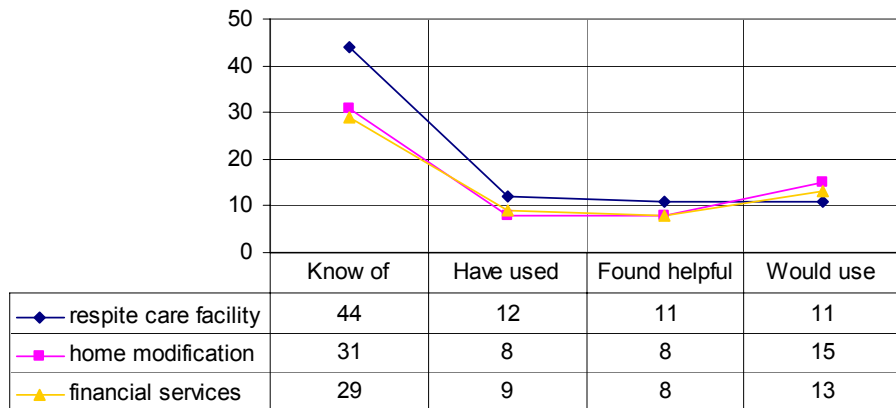


## Portion of Care Provided by

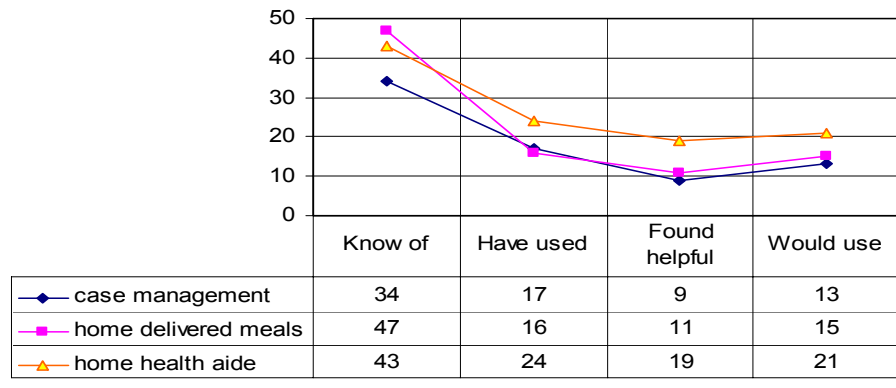




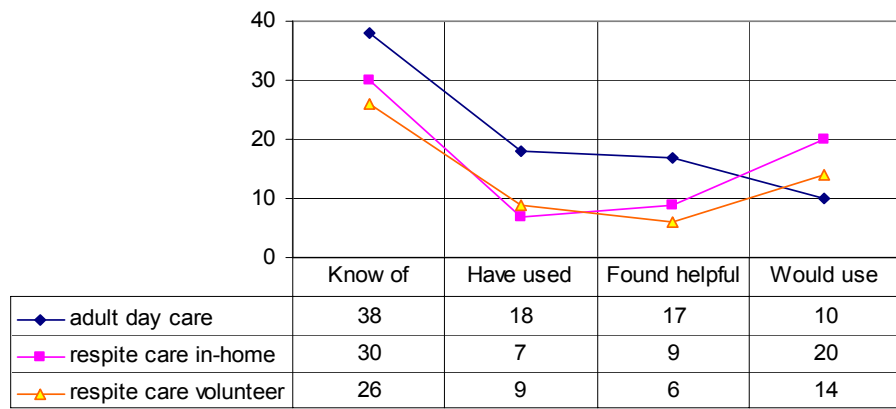
Trends in Respite care facility, Home modification, Financial services

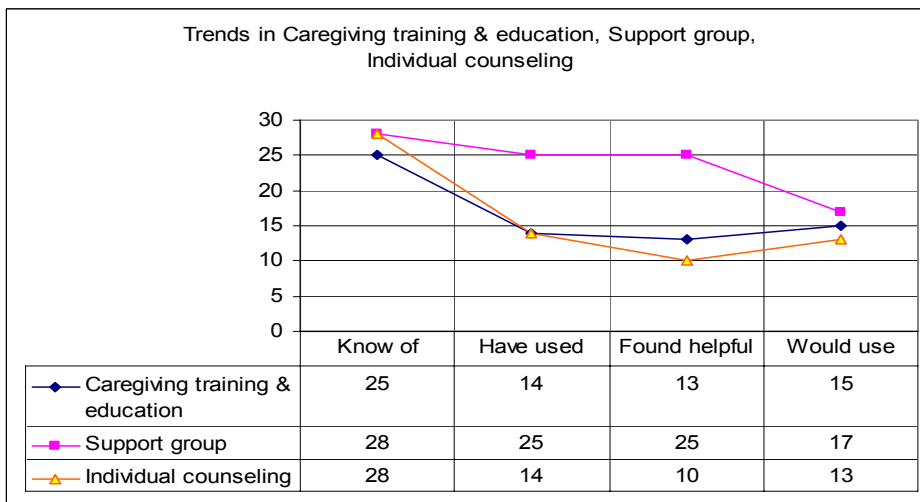
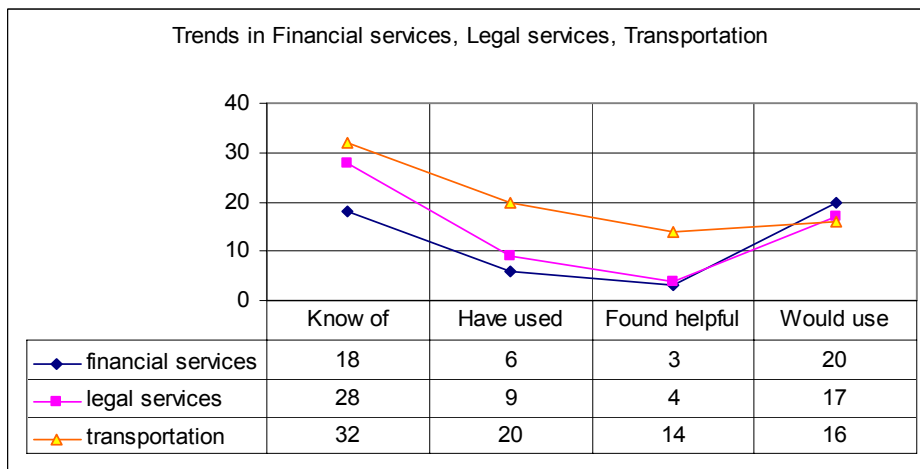
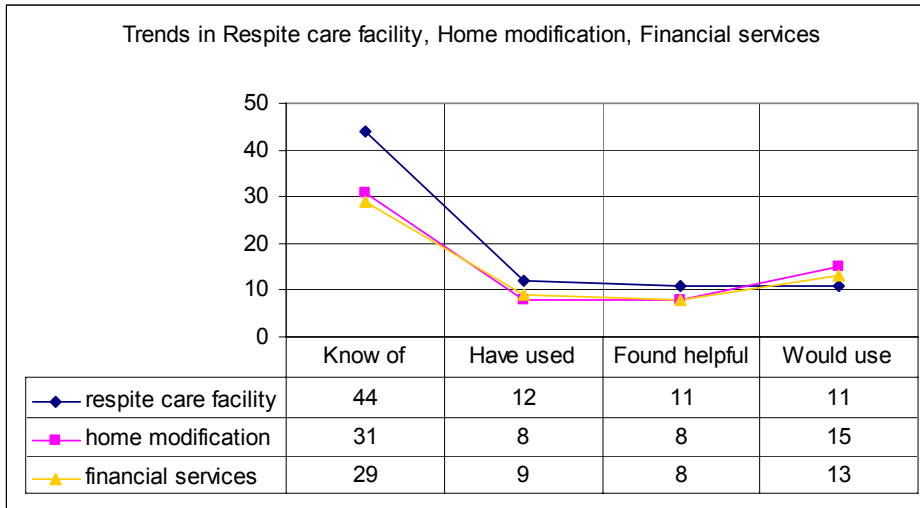


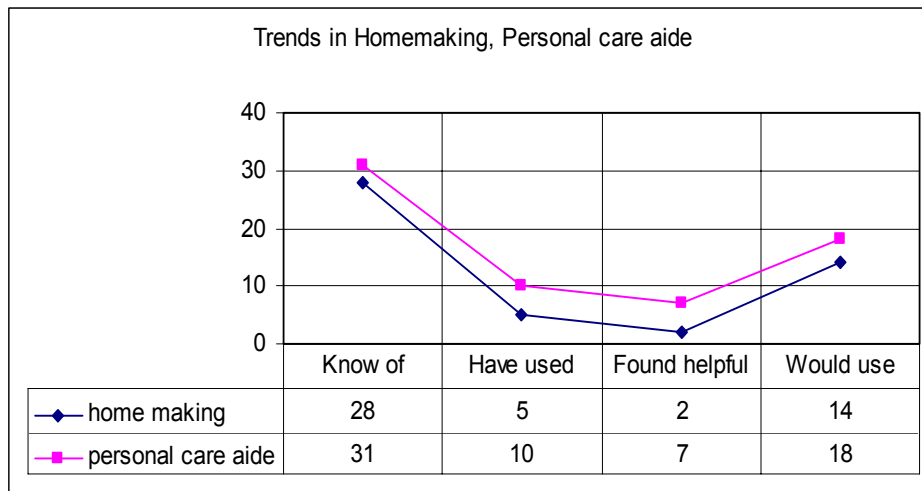
Trends in Case management, Home delivered meals, Home health aide



Trends in Adult day care, Respite care in-home, Respite care volunteer







Question 15 was open-ended and asked people the following, “Of all the services you have used in the past, or are currently using to help you give care, which was the most helpful and why? While there were numerous responses, most of them could be clustered into these six categories:

1. Respite care, both in-home and site-based
2. Adult day care
3. Transportation (to both services and to manage household issues)
4. Professional services, particularly for legal and financial advice
5. Personal & emotional support, from family, friends, volunteers or paid counseling
6. Someone to help them negotiate the system e.g. case manager or ombudsman

#### V. RSVP Survey –Overview of Results:

RSVP volunteers were asked to indicate the extent of their agreement, using a 5-point scale with the following 5 community service areas. Extent of agreement ranged from: “ Strongly Agree; Agree; No Opinion; Disagree; Strongly Disagree.”

1. Knowing where to go to find information about the help I need
2. Support for family members, friends and others who care for someone who is frail
3. Help that is available and that meets my needs
4. Services and assistance I can afford
5. City leaders who are educated about the needs and preferences of older adults

In all 5 community service areas, almost all respondents (63.1% - 74.5%) gave a rating of, “Strongly Agree.”

In no order of priority, 51 of the 143 (37%) respondents also listed the following other community services areas as important to them: Transportation; Socialization; Health Care; Meals/Food assistance; Financial assistance and advice; Programs and Services; Independence; Community involvement; Information and Referral; Professional support; Physical/motor activity; and Home repair and maintenance.

To the question, “Where do you see yourself living in the next 5 to 10 years?” 88 out of 124 (70%) responses were, “At home/In my present home.”

To the question, “What kind of help, if any, do you think you will need to be living there?” 77 respondents listed these services/supports in order of frequency: Transportation/Yard Work (equal number of responses); Cleaning; Home Repair/Maintenance; Health Care (both in home and facility based); Financial assistance e.g. taxes; Housekeeping/Chores; Meals; Support from Family/Neighbor/Friend; Home Modifications; Help with Shopping & Appointments; Social e.g. field trips; Assisted Living; Privacy; Independence; Nursing Home; and Help with moving/selling home.

## **VI. Survey of Professionals:**

During July 2005, 12 area professionals specializing in services to caregivers and their families met to discuss a variety of services and issues in 4 categories that are needed for effectively supporting family caregivers. The full list of services can be found in Attachment D.

The services listed below are those that were mentioned repeatedly by these professionals:

1. Help Caregivers are seeking
  - Financial assistance
  - Assistance with housing issues
  - Respite care in and out of home
  - Affordable in-home help
2. Barriers to Existing Services
  - Lack of affordable assisted living
  - Lack of understanding in how to access services
  - Inadequate knowledge of existing services
3. Gaps in Services for caregivers
  - Respite and day services for caregivers of those without memory loss

- Respite for grandparents
  - Affordable home health services
  - Transportation
  - Emotional support for caregivers
4. Upcoming trends/things to pay attention to for the future of caregivers
- Care for elder family members in home
  - Affordability of in-home care
  - Increase in senior day services and facilities

## **VII. Respite Service Capacity and Costs:**

On August 26, 2005 a telephone survey of area respite service providers was completed. The provider agencies to be called were determined by using the list of provider agencies compiled by the University of Michigan Geriatrics Center. This short telephone interview was to determine cost and capacity information from both non-profit and for profit respite service providers. The brief questionnaire that was used and the resulting, "Summary of Local Respite Service Provision," can be found as Attachments E and F respectively.

Hourly rates for both non-profit and for profit agencies are similar and tend to range from \$16-\$20 an hour. Daily rates were from a low of \$125 per day to \$240 per day. The range of services is variable and the definition of a "day" is variable, as well depending on whether services were for a day program or included an overnight stay. The telephone surveyor found that obtaining information could at times be difficult, especially from for profit organizations, when her interlocutor was impatient about answering questions for public planning purposes. As an alternative approach, with some organizations she asked for information for a "friend" who might need respite services. In those cases, she was able to obtain more information.

## **VIII. Final Comments and Implications:**

The fact that people are living longer and that many of us will need to receive care from a caregiver at some point in our lives is indisputable. In the early years, people are taking longer to become fully prepared for adult life, and at the other end of the life span, people are living longer. One RAND Corporation study cited by the New York Times columnist David Brooks suggests that 40 percent of people living into old age will eventually suffer from some form of dementia. Given the demographic "goat in the python" of the aging of the first of the baby boomers, the implications are clear that perhaps even some millions of people will need caregiving. The President's Council on Bioethics report, "Taking Care: Ethical Caregiving in Our Aging Society," discusses, among many other issues, the changes in society that are beginning to emphasize the importance of the family as the fundamental unit of society, rather than the individual.

Given these considerations, this small, local report gives us some guidance on where local policy-makers and program professionals should direct their individual and collective energies. Respondents to the various surveys, questionnaires and focus groups consistently want the system of caring and of caregiver support to provide the following:

1. First and foremost, that there be an actual “system” of care that is coordinated and within which professionals at all levels communicate with each other and with family caregivers. Caregivers find the challenges of ferreting out community resources (public, nonprofit and private) on their own to be exhausting. Of particular note, “educating physicians about the issues facing caregivers,” came up repeatedly.
2. Affordable supports; respite services, both in-home and site-based; adult day care, home health care; home help and transportation assistance are among the highest priorities.
3. Affordable senior housing with on-site services is also cited as priority area. Specific models of supportive housing remain to be articulated and prioritized.
4. Caregivers typically do not resent their role. However, many caregivers have expressed that they would like to see caregiving be given more respect, and that caregiving responsibilities be shouldered by more than the typical single individual family member who steps up. This sentiment has implications for both families as the primary social unit being supportive of one another and for social policy to support those families.
5. Financial assistance and legal assistance e.g. wills, trusts, power of attorney issues are higher priority needs cited by many respondents and professionals.

## Attachment A

### Survey Questionnaire

1, What is your age? (Please check the appropriate category)

30-39     40-49     50-59     60-69     70-79     80+

2, Are you  Male  Female

3, What is your marital status?  Married  Divorced  Widowed  Single

4, What is your race/ethnicity?

Caucasian     African American  
 Asian \_\_\_\_\_ (specify)     Hispanic/Latino \_\_\_\_\_ (specify)  
 Native Hawaiian or other Pacific Islander  
 American Indian/Alaska Native     Other: \_\_\_\_\_ (specify)

5, Are you currently working outside the home? \_\_\_\_\_

If yes,  full time  part time

6, What is your zip code? \_\_\_\_\_

7, What is the age of the person for whom you provide you care? \_\_\_\_\_

8, What is your relationship with this person?

Spouse     Parent     Child  
 Other Relative     Grandparent     Other

9, Do you live with the care recipient? \_\_\_\_\_

10, How long have you been providing help to the person for whom you are caring?

\_\_\_\_\_  
11, How often do you provide care to this person?

less than one day a week     several times a week  
 weekly     daily  
 monthly     occasionally

12, How many hours do you spend giving care to this person each week? \_\_\_\_\_

13, Thinking about all the family members and friends who provide unpaid help, care or supervision, what portion of the care do you provide?

- All     
  Nearly All     
  More than one-half, but not nearly all  
 About half     
  More than a little, but less than one half     
  A little

14, Please complete the grid below. Indicate with a check mark (√) the services you know of, have used, or are currently using to help with Caregiving and which services you found helpful. Please also indicate the services you are not using, but would use if available.

Know of; Have used; Find helpful; Would use

Case Management				
Home Delivered Meals				
Home Health Aide				
Adult Day Care				
Respite Care – in home				
Respite Care - volunteer				
Respite care - facility				
Chore Services (home maintenance)				
Home Modification				
Financial Services				
Legal Services				
Transportation				
Caregiving Training & Education				
Support Group				
Individual Counseling				
Homemaking				
Personal Care Aide				

15, Of all the services you've used in the past, or are currently using, to help you give care, which was the most helpful and why?

## Attachment B

### Family Caregiver Focus Group Questions

Welcome!

“Let us go around the table and please tell us your name and briefly a little about your current Caregiving situation.”

1. A caregiver can be defined in a variety of ways. One definition that we came up with is *A person related by birth, marriage, adoption or emotional ties who provides psychological, emotional, spiritual, and/or physical support.*”

Did we leave anything out in your opinion?

2. What would you say are the positive aspects or satisfactions of being a Caregiver?

3. What are the obstacles (maybe say “greatest challenges”) that you experience as a caregiver?

- further probing question: Do you have needs that are going unmet?

4. Was there a turning point when you realized that your situation became unmanageable for you to handle on your own?

5. What help do you need to be a caregiver? (for example, more help from a family member or more formal services such as a support group?)

6. What would an ideal support system be for you?

## Attachment C

### Town Hall Meeting Family Caregiver Support Breakout Session Notes

Sample: approximately 20 participants, all Caucasian, 2 males/ the rest females, even mix between older community members and representatives from service agencies both non- and for-profit

Public feedback and reactions to proposed major issues and recommendations  
(in order based upon # of prioritizing dots received, which are listed)

- Educating physicians (4)
- Affordable senior housing with on-site services is the way to go; some older adults don't want to stay in their own home (3)
- Unaffordable respite care is a problem (3)
- A caregiver might feel disempowered by accessing the service system; this person does not want to lose their ability to make decisions for their loved one; feeling of having their decision making abilities minimized (2)
- Parents of adults with developmental disabilities can be an overlooked group: who will care for their adult child while the family receives respite? (2)
- More education re: borrowing equity of one's home (2)
- Having a local place to call to get information; a "clearinghouse" and case management (2)
- Caregivers save the county lots of money (1)
- No resources in rural areas – this causes families to have to uproot their loved ones and move where the resources are (1)
- Include all caregivers in the planning – including parents of adult children with disabilities (1)
- Long-term respite of one to two weeks is needed (1)
- Data system with information on services is needed (1)
- Some feel overwhelmed by the amount of information on the Internet and prefer to speak with an actual person (1)
- Have more public forums geared toward self education and planning for the future (1)
- "Home of choice" – inclusive of those older adults wanting to stay in their own homes and those who wish to move into a retirement community, etc
- People might not know what their options are
- Families need to talk to one another
- Moving a frail older adult between respite and home can be hard
- Problem of people not paying attention to services available until a crisis happens
- Asking for help might be seen as being too needy; the "we take care of our own" attitude means not optimizing existing services

- Mistrust of the system
- It is sometimes hard not to feel hopeless as a caregiver

#### New Ideas Proposed by the Public

(in order based upon # of prioritizing dots received, which are listed)

- training and screening for respite care workers and home health aides is important (5)
- Someone to call and follow up/check in on a caregiver who might not want to call a help line (5)
- Not everyone knows about caregiver mediation services – use 211 and physicians to refer people to these services (3)
- Virtual support groups and chat rooms (1)
- Lifespan respite similar to the Community Respite Center in Jackson, MI
- 211 to offer a crisis line? (1)
- Lobby government for more funding of programs for caregivers (1)
- Hold forums at senior centers (1)
- “Lunch and Learn” programs at places of employment (1)
- revamp current services (1)
- Medical providers could serve as consultants to caregivers
- Uniting caregivers outside of support groups in an informal way is important
- What happens after a person’s caregiving role ends? There should be mechanisms in place to help caregivers pick up the pieces and move on with life (ex: re-entering the workforce)
- Increase advertising of services and support
- hold trainings and classes for caregivers at YMCA or community college
- do more outreach to churches by offering educational presentations

#### Proposed Family Caregiver Support Recommendations for Public Feedback

(in order based upon # of prioritizing dots received, which are listed)

- Increased education for caregivers, physicians, employers, and the general public (6)
- Increase the amount of respite services and adult day programs in the county (4)
- Provide training on caregiving in religious organizations and the general community (2)
- Develop a strategy to provide consultation assistance to caregivers (1)
- Develop the capacity to provide support to family caregivers on a 24 hour/7 days a week basis

#### Proposed Family Caregiver Support Major Issues for Public Feedback

(in order based upon # of prioritizing dots received, which are listed)

- Beneficial education and support programs reach a fraction of caregivers (5)
- The way family caregivers gain information about and obtain assistance could be improved (5)

- Family caregivers can benefit great from “respite” care that provides periodic relief from daily stresses (4)
- Current “respite” services do not meet the need (3)
- Assistance to support family caregivers is insufficient and can be unaffordable (2)
- Caregivers receive satisfaction from their role but also face great challenges and obstacles (1)
- Current services are under-utilized
- Family caregivers provide the vast majority of supportive care, not medical systems or institutions

## **Attachment D**

### **Results of Survey for Professionals July 2005**

Information was collected from 12 professionals who provide a variety of different services to individuals and families in Washtenaw County.

#### **1. Help Caregivers are seeking**

- Legal services
- Assistance with guardianship issues
- Medication
- Financial assistance/affordability
- Child rearing, boundary setting (grandparents raising grandchildren)
- Assistance with housing issues\*
- Referrals for out-of-state resources
- Respite care in and out of home\*
- Long and short-term care
- Affordable in home help\*
- Services for grandparents raising grandchildren with developmental disabilities
- Home Meals
- Assistance finding medical equipment
- Advice on choosing housing
- Advice on Medicaid and Medicare
- Transportation

#### **2. Barriers to existing services**

- Inadequate staffing for case management
- Lack of affordable assisted living\*
- Lack of affordable companionship services
- Lack of affordable in home cleaning services
- Lack of understanding in how to access services\*
- No comprehensive and succinct information on SSI and SS benefits, other long term care insurance
- Not enough hours of service available
- Inadequate knowledge of existing services\*
- Descriptions of services available are confusing
- Training on how to use computers to find services
- Lack of information about services that do exist
- Minimal publicity for services that exist
- Many people don't identify themselves as caregivers

### **3. Gaps in services for caregivers**

- Respite and day services for caregivers of those without memory loss\*
- Respite for grandparents\*
- Affordable home health services\*
- Affordable assisted living
- Affordable day care
- Transportation\*
- Emotional support for caregivers\*
- No public recognition of caregivers
- Support and programming for early stage memory loss
- Easy internet access
- Emergency services for caregivers

### **4. Upcoming trends/things to pay attention to for the future of caregivers**

- Higher subsidies for grandparent headed households
- Care for elder family members in home\*
- Affordability of in home care\*
- Bathing services
- Facility based respite care where caregivers can get up to two weeks off at a time
- Single parent caregivers
- More focus on single families
- Technology to monitor safety, medications, and food
- Eden Alternative
- Resources will continue to be cut
- Large increase in the number of caregivers
- Rebellious younger caregivers unwilling to spend more time and money for services
- Policy changes at work for those who are caregivers (increased time-off)
- Continuum of care
- Increase in senior day services and facilities\*
- Increase in collaborative efforts
- Increase in family disputes
- Consumer driven care

\*Mentioned repeatedly by several different professionals

## Attachment E

### Respite Service Questions

Name of organization or program: \_\_\_\_\_

1. What type of respite services do you provide?

- In-home? \_\_\_\_\_
- Site-based? \_\_\_\_\_
- Kinds of activities/services provided as a part of respite \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. What hours and days are respite services available?  
\_\_\_\_\_

3. What are the costs, and  
\_\_\_\_\_

4. What method(s) of payment do you accept?  
\_\_\_\_\_

5. What is your capacity for service (how many can be served at any one time)?  
\_\_\_\_\_

6. Do you maintain a waiting or priority list? \_\_\_\_\_

If so, how long does it typically take to begin receiving respite services? \_\_\_\_\_

How many people are on the waiting list? \_\_\_\_\_

## Attachment F

#	List of Agencies	Contact Person	Telephone	Respite Service Description	Cost	Capacity
1	Michigan Visiting Nurses	Karen Capp	677-4515	Yes. Our major business is to provide private care (visiting care)  <a href="http://www.umvn.org">www.umvn.org</a>	Three different types of services: RN: REGISTERED NURSE, \$47/hr LPN: LICENSED PRACTICAL NURSE \$41/hr HOME NURSE:\$23.75 /hr	Capacity really depends on staff availability. We can serve up to 35 people for home care, but only 5 people for respite.
2	Fairfax Manor	Karen	483-6662	Yes. Adult day service. Overnight/Short-term Residential Care. Provide assisted living for people with memory loss. It is sponsored by Area Agency for Aging. Services are based on the type of needs and the duration. Customers are sent here by 'area agency', 'area agency' will provide us with background information. Customers pay 'area agency', then area agency pay us in lump-sum.	\$145 /day /person. We provide 3 meals plus snacks plus 24 hour care.	40 rooms (one bedroom w/ bathroom). Service depends on how many rooms are available.
3	Brecon Village		429-1155	Yes. Both short-term and long-term contracts are available. It varies from 1 week to 8 weeks. Care-seekers sign the contract before they move in.	\$130/day for single person, \$200 for couple / family. Which include 3 meals and care.	We have 32 assisted living apartments which can accommodate both singles and couples. Customers pay for the extended period of care if they extend the lease.
4	Watson Health care	Debra	528-5056	Yes. Our staff includes nurses, PT/OT. They will do the assessments. Service is home-based. Nurses go to patients' home for care.	\$18/ hr--\$20/hr, 24 hr, up to 3 days	No problem with staff availability. We have 3 agencies in Michigan
5	First choice	Denise	1-800-548-3467	Yes. Overnight / only non-medical live-in service. All kinds of care are included such as laundry, housekeeping, meals, medication reminder, etc.	Up to two weeks (14 days). \$160 /day	No problem with staff availability.

				(Headquarters is located in Rochester, MI) <a href="http://www.firstchoicebestchoice.com">www.firstchoicebestchoice.com</a>		
6	Friends Who care	Shawn	1-800-288-2167 or 971-6300	Yes. We provide wide range of services such as personal care, housekeeping activities. We will try to find employees whose schedule matches the clients' schedule. After our assessment, employee will provide home-based services. <a href="http://www.friendscare.org">www.friendscare.org</a>	\$18 /hr, at least 2 hours.	No problem with staff availability.
7	Area Agency on Aging (AAA 1-B)	Vikki	1-800-852-7795 or 213-6704	Yes. Both in-home respite and out-of-home respite. Overnight/Short-term Residential Care. Two week limit on overnight stays Service is really based on funding we receive.	\$16--\$20/hr	Right now, we can only provide in-home respite for only one person.
8	AMAG Superior Homecare Inc		663-8319	Yes. In-home respite and out-of-home respite.		
9	Help source	Shirley	973-1900	Yes. In-home service.	\$16/hr	
10	Home Instead Senior Care	Greg	971-9023	Yes. In-home service for senior citizens. Non-skilled services Specially trained staff Life line available <a href="http://www.homeinstead.com">www.homeinstead.com</a>	\$17--\$19/hr depends on the nature of the service (errands, transportation, Alzheimer's care, meal preparation, light housekeeping, etc.)	No problem with staff availability
11	Visiting Angels		929-9201	Yes. In-home service. Non-medical care, personal care, companion services.	\$18/hr \$32/2 hrs	
12	Silver Club	Beth Spencer	998-9352	Yes. Service for old people with memory loss.	We charge based on old people's income. If the customers are couple, we charge based on couple's income. The cost varies	Serve up to 18 people by screening process. We do a lot of paperwork before starting the service.

					from \$2 /hr to \$14/ hr.	
13	Catholic Social Service	Connie	712-3625	Yes. In-home service. Volunteers provide respite 1-4 hours/week to relieve the full time caregivers of the frail elderly. Trained volunteers assist frail, at-risk, older adults and caregivers with respite care, friendly visiting and telephone reassurance.	No charge for the client with chronicle illness. Criteria: either caregiver or recipients are elder adults in their 60s.	18-19 volunteers work with 20-24 family.
14_1	Sunrise at Ann Arbor North	Toni Bonner	741-9500	Yes. In-site Respite Care is offered in these assisted living facilities, space permitting.	\$125/ day (room rate + meals) \$27--\$42 extra cost for care. Need \$500 deposit.	73 people, but really depends on availability. Temporary resident stays of up to two weeks are available.
14_2	Sunrise Assisted Living	Jennie	327-1350	Yes. In-site respite. At least two weeks, at most three months.	\$150/day (almost include everything.) Rate depends on price of room, care level.	
15	Generations Together	Bernadette Lewis	426-4091	Yes. In-site. 8am-5pm Children & adults	\$50/day (include lunch & afternoon snacks) One-to-one caregiving.	
16	Kennedy Care	David Kennedy	657-3528	Yes. In-home service Skilled and non-skilled care	\$16-\$18/hr 24/7 one-to-one care	
17	Health & Home Services Unlimited	Megan	517-849-4663	Yes, In-home respite. Plan to have branch in Chelsea.	\$16-\$18/hr for in-home visit.	Really depends on how intensive the care is. Staff is available 24 hrs.
18	Glacier Hills Nursing Center Respite Care	Julie Trinkle	769-0177	Yes, in-site respite. We have both temporary and long-term care. Clients need to fill some application form to meet the financial criteria.	\$235/24 hrs for ADL service extra cost is needed for extra service we need know clients' medical history.	161 nursing residents.
19	Heartland Health Care Center	Destinie Adams	975-2600	Yes. In-site respite. Overnight/Short-term Residential Care. We need know the medical history.	\$184/ day include 3 meals and snacks.	180 people
20	Silver Maples	Tammie Mccarron	475-4111	Yes, in-site respite short-term care. Staff will do means assessment.	Four different levels \$2930 per month	61 apartments /176 residents

				24 hr care; Really based on how much care does the person need.	up to \$4360 per month	
21	Arbor Hospice and Home Care		662-5999	Yes, Only respite for hospice patient. In-site.	\$220 per day. \$240 to live in private rooms \$3000 deposit is needed	Currently there are 30 persons in their facility. The facility is full.
22	Care one, Inc.		480-0011	Yes, respite. At least 2 hours.		
23	Great Lakes Home Health Care	Donna 517-796-1722	517-266-1700 or 800-379-1600	Yes, respite 24-hour on call service Hospice and palliative care Home medical equipment Lifeline available <a href="http://www.glhhs.com">www.glhhs.com</a>	No charge for assessment. Need to talk with clients to understand their needs first.	No problem with staff availability
24	Gentiva Health Services		677-1661	Yes, in-home respite Different therapies <a href="http://www.gentiva.com">www.gentiva.com</a>	\$35 for one hour visit \$39 for 2 hrs visit \$18/hr for 4 hrs and more (Mon-Fri) \$19/hr for weekends Non-skilled nurse-helping activity Rate is really based on needs.	
25	Option one		677-3800	No respite Only home care		
26	Total Care, Inc.		484-9820	No respite Skilled Care Service		
27	St. Joseph Mercy Home Care		327-3200	No.		
28	Neighborhood Senior Service		712-7775	Only serve Milan school district		
29	Glacier Hills	Cindy	769-5758	No respite service, only private care.	The cost of nursing is \$50 / hour. In general, the costs depend on the types of services.	
30	Arbor care	Olidia	975-6608	No respite service. We only provide care to poor children. There is one worker per shift.		
31	Aid in Milan		439-8420	No respite. In-home service		
32	Faith in		475-3305	No respite.		

	Action			Only emergency caregiver service		
33	Jewish Family Services		971-0990	No respite		
34	Alliance Personal Care		665-9095	No respite.		
35	Chelsea Care Home Health		475-4190 or 1-800-943-4663	No respite Only home care		
36	Home care and Hospice of Michigan		769-4212	No respite		
37	Kelly Home Care Services		866-835-3385	Skilled and non-skilled services Companion services Specially trained staff <a href="http://www.kellyhomecare.com">www.kellyhomecare.com</a>		
38	Visiting Physicians Association		975-5000	No respite Only housecall.		
39	On Golden Pond		482-6170	Adult Day Service		
40	Apria Healthcare					
41	Grandma Goes There		996-5925			
42	Comfort Keeper		426-5080			
43	Commercial service		800-884-3150			

Note:

1. A few agencies did not recognize the term “respite.”
2. Some agencies provide Home Care, but they do not define it as respite service.
3. There should be more communication between respite provider and home care provider since certain types of services overlap.
4. The rate for respite services is almost identical across agencies.

