Appendix G

Caregiver
Caregiver Focus Groups

To characterize the needs of Alabama caregivers, the Alabama Department of Senior Services (ADSS) and the Alabama Research Institute on Aging (ARIA) of the University of Alabama partnered to conduct a series of focus groups with family caregivers. Participants were asked to give their opinions on what the top issues facing Alabama caregivers are, and what measures might be taken to help meet those needs. In all, six of the seven Congressional Districts were represented; scheduling problems prevented completion of the group in District 1.

Sample characteristics. Table XX shows characteristics of the 63 caregivers who participated in the focus groups. Reflecting national data, focus groups were predominantly female and ranged in age from 31 to 82 years. Respondents were disproportionately African American, mainly because of recruitment differences at different sites. A broad range of caregiving experience was represented: one respondent had been providing care for only one month, another for more than 30 years. Of the 58 caregivers who answered our question about relationship to the care recipient, half provided care to their mothers; a third cared for a spouse. Six had cared for multiple family members and/or friends either currently or in the past. Notably, several participants were professional as well as family caregivers.

Care recipients suffered from a variety of health problems, and most had multiple chronic illnesses. Alzheimer’s disease or other dementia was the most common, cited by two in five (39.7%) of focus group participants. Other problems for which respondents provided care included stroke, mobility problems and “old age” (14.2% for each), heart problems and arthritis (12.7%), diabetes (9.5%), hypertension (7.7%), and cancer (6.3%).

Identified concerns. Each focus group was asked to list the major issues or concerns facing family caregivers. No further instructions were given, but groups were reminded that the

<table>
<thead>
<tr>
<th>Characteristics of focus group participants</th>
<th>N (%)</th>
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<tbody>
<tr>
<td>Female</td>
<td>48 (76%)</td>
</tr>
<tr>
<td>Male</td>
<td>15 (24%)</td>
</tr>
<tr>
<td>African American</td>
<td>35 (56%)</td>
</tr>
<tr>
<td>White</td>
<td>27 (43%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Current caregiver</td>
<td>47 (77%)</td>
</tr>
<tr>
<td>Former caregiver</td>
<td>14 (23%)</td>
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<tr>
<td>Live with care recipient?*</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>42 (68%)</td>
</tr>
<tr>
<td>No</td>
<td>19 (32%)</td>
</tr>
<tr>
<td>M (SD)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>63.8 (9.6)</td>
</tr>
<tr>
<td>Years as a caregiver</td>
<td>6.5 (5.5)</td>
</tr>
</tbody>
</table>

NOTE: Numbers may not sum to 63 because of missing responses on some items.

*Now or in the past
focus should be on concerns that the State of Alabama might help address. Although each group expressed some unique concerns, a number of common themes emerged. Table XY summarizes the 10 broad issues that were noted by at least two of the 6 focus groups.

The most commonly cited issues facing family caregivers, each raised in 5 of the 6 groups, were financial burden, need for respite, and concerns about the caregiving workforce. Discussion of financial burden addressed the costs of providing informal care and the need for affordable services and programs. A common theme was the lack of support for middle-class caregivers, whose loved ones may not qualify for services through Medicaid or other means-tested programs. Several groups called for review of healthcare financing to identify changes that could relieve the financial burden faced by family members. Others noted the need for information and assistance in financial planning, not only for long-term care but also for everyday “incidental” costs such as purchasing continence care supplies or other needed items. Several participants noted that the latter, everyday costs often come as a surprise to caregivers, and can represent a substantial budgetary strain.

Respite care was also identified by 5 of the 6 groups as a pressing concern. Caregivers emphasized the need for rest and relief at two distinct levels: not just an occasional “vacation” from caregiving, but also daily respite to take care of routine household business and other family concerns. Both forms of respite—personal time on a daily basis as well as an occasional “real break” from the stresses of care provision—were strongly valued. Focus group participants praised currently available respite programs, including adult day care programs. However, caregivers emphasized that these services need to be expanded and enhanced to meet caregivers’ daily needs, e.g., through in-home respite programs.

Concerns about the professional caregiving workforce, raised by 5 groups, centered on the availability of affordable, quality professional care. Several groups decried the lack of “good help” in daily care. Patience and caring attitudes are highly valued in paid caregivers, but

<table>
<thead>
<tr>
<th>Topic</th>
<th>Number of groups</th>
</tr>
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<tbody>
<tr>
<td>Financial burden</td>
<td>5</td>
</tr>
<tr>
<td>Respite</td>
<td>5</td>
</tr>
<tr>
<td>Workforce / paid care</td>
<td>5</td>
</tr>
<tr>
<td>In-home care</td>
<td>4</td>
</tr>
<tr>
<td>Long-term care planning</td>
<td>4</td>
</tr>
<tr>
<td>Access to information</td>
<td>3</td>
</tr>
<tr>
<td>Stress</td>
<td>3</td>
</tr>
<tr>
<td>Caregiver support</td>
<td>3</td>
</tr>
<tr>
<td>Environmental support</td>
<td>3</td>
</tr>
<tr>
<td>Other specific needs</td>
<td>3</td>
</tr>
<tr>
<td>Findings from six focus groups conducted throughout the state of Alabama, Sept.–Nov. 2015</td>
<td>3</td>
</tr>
</tbody>
</table>
professional training is sometimes lacking. Dementia care was noted as a specific training priority for professional caregivers; Affordability was a second strong theme with regard to the caregiving workforce, reflecting concerns about the financial burden of family care outlined above. One group raised the question of licensed vs. unlicensed help, as a trade-off of skills vs. affordability.

_In-home care_ (4 groups) was identified as a key contributor to caregivers’ ability to keep their loved ones at home. Home care was clearly preferred over institutionalization not only on financial grounds, but also to preserve quality of life of the care recipient. This issue was closely related both to financial burden, particularly the affordability of home care, and to workforce issues, in terms of the quality of home care services currently available. One respondent stressed that in-home medical care also helps relieve family member’s caregiving burden, stating that it took 2-3 hours just to prepare her care recipient to leave the house for a medical appointment.

The next two themes addressed need for caregiving information. A diverse group of concerns, voiced by 4 of the 6 groups, converged on _long-term care planning_. A first subtheme was the importance of personal planning, particularly being prepared to make changes in one’s own lifestyle to accommodate care provision and the care recipient’s needs. A second was advance care planning. Here, respondents specifically mentioned legal issues and the need for caregiver information on legal competency, advance directives, end-of-life care and other aspects of medical decision-making. Finally, two groups emphasized the importance of communication with other family members in planning informal care.

_Broader information needs_ of family caregivers were described by 3 groups. Emphasis here was on accessible, easy-to-find information about caregiving generally as well as available services and how to obtain them. A subtheme was the need for specific information and skills training, for example, in how to use durable medical equipment or specifics of home care following care recipients’ discharge from hospital.

Although _caregiving stress_ was discussed specifically by only 3 groups, it was a strong underlying theme in all 6. In two groups, the first response to our initial question, “What are the issues facing family caregivers?” was a resounding “It’s stressful!” Specific sources of caregiving stress include the time and energy involved in direct care provision, dealing with role reversal (being “the parent to my parent”), and the care recipient’s resisting care from family or paid caregivers. Other family members were also cited as a source of stress; here, the emphasis
was on improving communication within the family to improve quality of life for both the primary caregiver and the care recipient.

Caregiver support was identified as a strong need by 3 of the 6 groups. This theme was distinct from that of information needs in that it emphasized emotional support for dealing with the stresses of care provision. In addition to traditional caregiver support groups, respondents suggested in-home support, including one-on-one contact and volunteer assistance, as potentially helpful programs. “Village-to-village” community support was also cited as a valuable resource.

A final specific theme was environmental support (3 groups). A first major need was for help in obtaining durable medical equipment, particularly items that are not traditionally supported by Medicare or Medicaid, and for which rentals may not be available (e.g., walk-in tub). Such items were valued not just to improve ease of care, but to help prevent falls or other accidents. Similarly, accessible and affordable housing was cited as a key to keeping frail care recipients living independently in the community.

A last category comprises a series of specific needs identified as potentially improving caregivers’ ability to provide care and to weather caregiving stress. Some examples are senior companion programs, nutrition programs (particularly home-delivered meals), and pet care for recipients’ pets. Caregivers also spoke cogently about the need for advocacy at the state level to ensure that their needs are salient to policy makers.

Acknowledgment: Patricia A. Parmelee, PhD, Director, Center for Mental Health and Aging, Professor, Department of Psychology, The University of Alabama, 2016
Caregiver Focus Groups

Auburn Caregiver Focus Group
Auburn United Methodist Church
The Epworth Center
137 South Gay Street
Auburn, AL
September 30, 2015 @ 12:00 P.M.

Top 10 Caregiver Issues
- Affordable sitters and respite care (current cost $10.00 to $16.00 hour).
- Pros/cons licensed versus non-licensed help.
- More access to information about supports/services for caregiver.
- More knowledge about durable medical/right choices to make for long term.
- Elder care laws-knowledge of.
- When competent versus non-competency- when you need to make decision- need to be informed early on how to plan.
- Having to be parent to parent- education, support, right information to make informed choices.
- Communication with family members- the talk (like conversation project).
- Employment money grows thin.
- Financial-difficult things you never thought of like having to pay for supplies like depends.

Bessemer Caregiver Focus Group
Exeter-Fairfax Senior Center
1500 Exeter Avenue South
Bessemer, AL 35020
October 16, 2015 @ 12:00 P.M.

Top 10 Caregiver Issues
1. Must have paid caregivers who have patience/caring disposition.
2. Medical equipment that might not be covered by Medicare or Medicaid: bed, tub. There are no rentals.
3. Taking time off-respite (long-term not temporary [a real break]) but more than 4-8 hours more than 5 days respite.
4. Enough money to care for someone at home- as nursing home- hire help- equipment, pay for supplies, etc.- Consumer-directed care- same money in home as Nursing Home- long-term help not temporary help (Alzheimer’s/Dementia long-term care) state not doing enough.
5. Home care-extended-medical home model- come to home (often take 2-3 hours to get ready to leave home).
6. 1 on 1 support partner - not just support group.
7. Respite/companion service just to get day to day errands, responsibilities done-not the same as a personal break (especially for 24hr -Dementia patient).
8. Advocacy for caregivers.
9. Senior companion program in all 13 areas.
10. Personal Choices program statewide.
Demopolis Caregiver Focus Group
Theo Ratliff Activity Center
306 1st Avenue
Demopolis, AL 36732
October 22, 2015 @ 12:00 P.M.

Top 10 Caregivers Issues
1. Stress and stress relief.
2. Being alone not having support.
3. Lack of rest.
4. Family other members- lack of attention for care received- Care Receiver only wants 1 person. More family contributions to help loved ones.
5. Need a little relief - A break (Respite)-Support Groups.
6. Have to have patience/adjust to their ways.
7. Have to change lifestyle completely, need accommodations.
8. Funding to help caregiver (cost what make to pay someone to stay).
9. Home health-dependable-healthcare at home-more government benefits-expanded to help keep at home.
10. Accessible housing/equipment such as walk-in bath (Medicare does not cover)-prevent falls-caregiver health safety.

Florence Caregiver Focus Group
Florence Senior Center (The Club)
450 Country Club Road
Florence, AL 35630
October 27, 2015

Top 10 Caregiver Issues
1. Lack of information to caregiver resources.
2. Lack of planning (need to plan) to prepare to be a caregiver.
3. Finding Respite support when needed (i.e. to go to the grocery store).
4. Financial planning is needed to be a caregiver (could enable caregiver the financial ability to care for a loved one).
5. Individual or way to identify a resource to care for loved ones’ pet.
6. Lack of instructions on how to care for a loved one or use equipment when they leave hospital or doctor’s appointment.
7. Lack of services for those who do not qualify for Medicaid services due to income above poverty level.
8. Education/training for caregivers in the areas surrounding: Dementia/Alzheimer’s, financial planning, community resources (i.e. farmers market).
9. Lack of workers who are trained to care for individuals with Dementia/Alzheimer’s.
10. Additional Caregiver support for those with no family (i.e. personal shopper, social contact/friendly visitor).
Top 10 Caregiver Issues
1. Caregiving is very stressful.
2. Lack of trust from the one being cared for ("Mom is always looking for her purse").
3. Caregiving is time consuming. Respite Care is needed (for those not in enrolled in the program) and additional Respite support needed "for caregivers when they need it" (expressed by currently enrolled caregivers).
4. Swapping caring roles is a challenge. Traditionally, the parent cared for the child, now the child has to take on role to care for a parent and "as a child you have to be respectful to best care for a loved one."
5. Finance is an issue. It is financially challenging to be a caregiver; lack of money.
6. Getting the care recipient to accept care from an agency is a challenge.
7. Insurance coverage limitations; limitations on how to pay for needed services.
8. Accessible housing and equipment for loved ones with a disability.
9. Being able to care for a loved one in their own home (care recipients they are familiar with their home).
10. Accessible and affordable transportation (especially for those with a disability).

Guntersville Caregiver Focus Group
Guntersville Senior Center
1503 Sunset Drive
Guntersville, AL 35976
November 5, 2015

Top 10 Caregiver Issues
1. Information/access to answers/information services long-term care planning.
2. Services (homemaker) to keep recipient home.
3. In home respite at home-to take care of own needs- break not just temporary.
4. Adult day care.
5. More affordable hours of services for care recipient.
6. Financial payments to caregivers- they cannot work.
7. If you have caregiver resources (financial/issues) - you both go broke keeping at home or at nursing home.
8. Free Elder Care Legal Education/one-on-one consult and group education to address early in life, Monthly/regular meetings for caregivers to get information/legal, etc. /support groups, include How to plan for end of life issues: probate, plan ahead, estate.
9. Review/change of how we finance healthcare/NH/Issues (you save you lose- you don’t government pay) what’s fair there?
10. Community-based village to village- people helping people, community support/socialization, relaxation and volunteers to help.