

CARING FOR THE CAREGIVER

WORK PLAN

Introduction: As the population of Fairfax County ages, there will be an increasing need for caregiving. For some, caregiving will be provided by formal (paid) providers. For most, if national data are reflective of the County, caregiving will be the responsibility of family and friends. Since this group is neither paid nor specifically trained they are referred to as informal caregivers.

This latter group is of increasing interest since the care they provide keeps the care recipient in the home and out of nursing facilities for a longer period of time than the condition might otherwise warrant. According to the AARP, in 2013 these informal caregivers provided approximately 37 billion hours of care to adults 18 years of age and older. This translates into \$470 billion in economic value that might otherwise be covered by federal and state governments.

The AARP report *Valuing the Invaluable: 2015 Update* (p.19) estimates that there are 1,030,000 caregivers in Virginia providing 956 million hours of care, with an imputed value of \$11.8 billion. Against a reported state population of 8,260,000, this means that roughly 12.5 percent of the state's population is engaged in caregiving.

Prior to developing this work plan a paper was prepared that reviews recent literature on caregiving (*Caregiving: Setting a Context*). If nothing else, this paper shows the variability inherent in the term "caregiver". There is no accurate estimate of the number of informal caregivers and the type of caregiving occurring in Fairfax County.

Furthermore, while **national data** collected by AARP and the National Alliance for Caregiving (NAC) suggests that roughly two of three caregivers **did not** use paid help in the twelve months prior to the AARP/NAC survey, this figure may be lower in an affluent area like Fairfax County. There also is the issue of remote caregivers, who are most likely to enlist such paid help.

The County and a range of non-profits (e.g. *Alzheimer's Association National Capital Area Chapter*; *Insight Memory Care Center*; *SPARC Solutions*, to name three) provide caregiver support and respite. However, this is mostly a "pull" environment where it is incumbent on the caregiver to identify and access the services.

Add to this are the facts, again taken from the AARP/NAC study (*Caregiving in the US*) that:

- The main problem or illness experienced by the care recipient is old age frailty related issues (14%) vs the next ranking Alzheimer's/confusion (8%).
- One in ten caregivers is 75 or older. Many of these individuals are caring for a spouse and are, themselves, experiencing chronic health conditions.

Caregiving can be of varying length. The "**typical**" caregiver according to AARP/NAC is a 49 year old female caring for a 69 year old female relative. She has been providing care for four years on average and spending just over 24 hours a week in providing care. She also is likely married and working full-time.

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Caregivers enter and leave the role from different paths. In most cases, they find themselves involved as the care recipient becomes less able to perform the major activities and incidental activities of daily living.

However, caregivers also can find themselves called to the role as the result of a hospitalization, which also places on them the burden of performing medical or nursing tasks, often without any (or with limited) prior training. This was my personal experience when, after a number of surgeries, my wife was called upon to perform wound care over a number of months.

The Challenge: We can safely assume that as the population of Fairfax County ages the need for caregiving will increase; and that most of this caregiving will be provided in the home and by unpaid/informal caregivers. It is likely that many of these caregivers, except perhaps those over 70, will be employed full or part-time.

The principal task of this initiative is to:

- Determine what caregivers need by way of information, services and support.
- Establish to degree to which these needs are being met at present.
- Project what the future needs of caregivers in Fairfax County will be and whether resources will exist to meet these needs.

This initiative must be framed with a recognition that County revenue for human services, as well as pressures on individual income, impact both the ability to meet present and projected caregiver and care recipient needs.

Objective: This initiative will seek to answer three questions:

- What are the current needs of caregivers in Fairfax County?
- Using an IS/SHOULD approach, what are the perceived gaps in meeting these needs.
- What are some potential future/longer term needs of caregivers that the County and non-profits must be prepared to address?

Time Frame: Answers to the first two questions will be developed by end of September 2016; an approach to the third question will be proposed by the end of June, and if deemed feasible, will be implemented by the end of 2016.

Tasks:

- **Needs and Gaps:**
 - Develop a preliminary list of caregiver needs based on the literature reviewed to date.
 - Develop a list of all services currently available to unpaid caregivers in the County, including for fee services.

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- Identify twenty individuals to serve on two panels: professionals and informal caregivers.
 - Conduct interviews with each panel member to refine the list of caregiver needs.
 - Using the refined needs list, develop a survey instrument that asks each panel member to rate each need on two dimensions:
 - Its current state of fulfillment (IS)
 - Its necessary state of fulfillment (SHOULD)
(The difference on the rating scale between the IS and SHOULD ratings represents the GAP.)
 - Conduct small group sessions with each panel to elicit suggestions as to how the perceived gaps might be closed.
 - Report findings and recommendations.
- **Future/Long Term Needs of Caregivers**
 - Conduct selected interviews with identified subject matter experts to develop an initial list for future caregiver needs.
 - Determine the feasibility of using a Delphi/Cross Impact Matrix or Scenario Planning Approach to develop an informal sensing mechanism for County Human Services/Aging professionals and volunteers to monitor trends that might impact caregivers and service delivery for caregivers in the near term future.

Discussion: the above tasks notwithstanding, we do not have a current count of unpaid caregivers in Fairfax County. An approach similar to that used in the AARP/NEC study (*Caregiving in the US*) would provide an answer, but would likely be cost prohibitive; and would only provide a snapshot of a moving target. The better approach, in my opinion, is to educate faith-based communities and homeowner associations/civic associations to assist with identifying caregivers in their communities. This approach will be explored with County staff in the early stages of the initiative and a feasibility determination will be made.

Note: Based on the findings from this research, the feasibility of some form of caregiver cooperative or collaborative will be explored if the findings support such an action.