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University of Maine School of Social Work

Eastern Area Agency on Aging

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Intergenerational Adult Day Services Needs Assessment Project Final Report

October 2018



University of Maine School of Social Work

Eastern Area Agency on Aging

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This report was completed with funding from the Maine Health Access Foundation.

Intergenerational Adult Day Services Needs Assessment Project Final Report

The Intergenerational Adult Day Services (ADS) Needs Assessment project grew out of a 6-month collaboration of stakeholders interested in creating an interdisciplinary, intergenerational ADS program in the greater Bangor area. The need for this program became evident through focus group research conducted during the fall of 2016 in which participants in the Bangor area were asked about what they thought would contribute to making the city a livable community. Respite services for caregivers and more intergenerational programs were identified as important factors (Wihry, Kaye, Crittenden, 2016). Furthermore, family caregivers in contact with the Eastern Area Agency on Aging (EAAA) frequently ask about the availability of respite services.

Bangor currently has one “social-model” ADS program—My Friend’s Place—operating two days a week for four hours, and serving 10 participants at a time. They also run a program called “Memory Joggers” for higher functioning older adults a third day a week, also for four hours. Until recently, Bangor also had a “health-model” ADS program at Westgate Manor, but that closed in 2016 when Westgate Manor had a change of management. The distinction between a social- and health-model ADS program has to do with staffing and services provided. Health-model programs serve clients with greater needs and are required to have nurse and social work consultants.

Research has shown benefits for consumers of adult day services through socialization and participation in activities (Debelko-Schoeny & King, 2010), and with documented improved mood and morale through psychosocial support (Gaugler & Zarit, 2001; Dabelko & Zimmerman, 2008). Family caregivers benefit through emotional and psychological relief from daily demands (Gaugler & Zarit), reduced worry and depression (Dabelko & Zimmerman; Gitlin, Reever, Dennis, Mathieu, & Hauk, 2006), and receiving the respite they need to pursue other activities (Gaugler & Zarit).

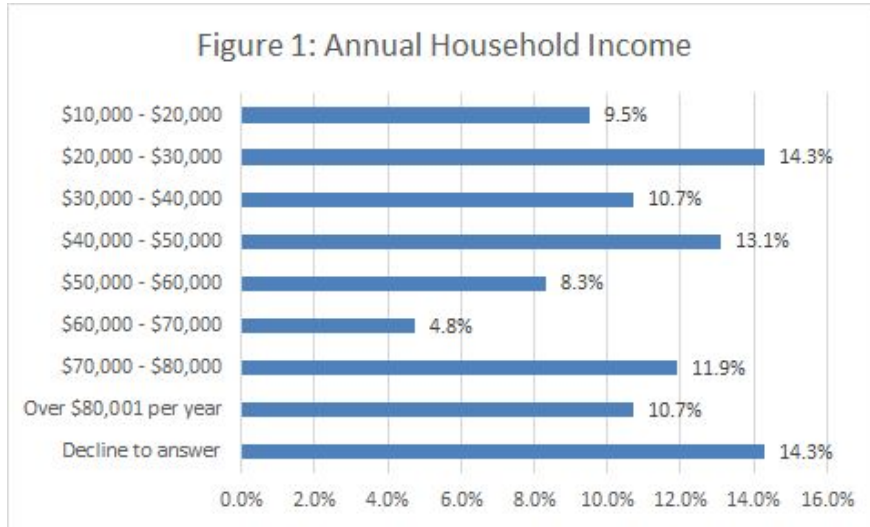
Upon receiving the MeHAF funding, the research team met to begin Phase I, the needs assessment. This involved constructing a caregiver survey, planning for data collection, and selecting potential key informants to interview. The Caregiver Survey was 5 pages long and was informed by a caregiver survey on respite services created by the Alabama Lifespan Respite Network (ALRN). (The Caregiver Survey can be found in Appendix A.). The survey was distributed through multiple methods, including Caregiver support groups in Orono and Bangor, SAVVY Caregiver classes, the Senior Expo, multiple health fairs, the EAAA electronic monthly newsletter, and through community providers. The survey was also mailed to caregivers who were either current or prior EAAA clients in the greater Bangor area. Caregivers had the option

to complete the survey instrument over the telephone, in person, online, or through a mailed paper version. Data were collected from February 5 through May 30, 2018. Eighty-four caregivers completed the survey and the data were subjected to descriptive and bivariate correlation analyses.

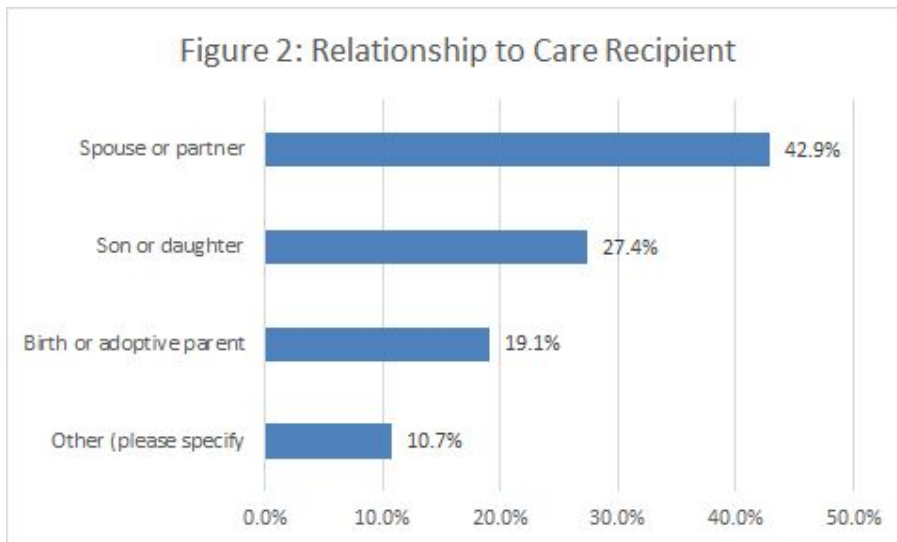
One member of the research team, Dr. Sandra Butler, conducted semi-structured interviews with the Directors and other key personnel at five ADS programs in Maine (two social-model and three health-model programs, including the existing program in Bangor). Interviews were also conducted with five individuals who work closely with older adults who could potentially use ADS services, some of whom had direct experience running ADS programs in the past. These individuals included directors of assisted living and continuing care facilities and the Maine Chapter of the Alzheimer's Association, as well as a mental health care provider for individuals in a mood and memory clinic at a hospital. A Recreational Therapist at an assisted living facility that sponsors a well-developed children's program was also interviewed. An additional interview was conducted with an employee of the Department of Health and Human Services who manages a funding program for older adults using ADS who are low-income but not eligible for Medicaid. All interviews were transcribed and deductively analyzed for key themes related to the interview questions. (The semi-structured interview protocol can be found in Appendix B.)

EAAA Caregiver Survey Results

Out of the 84 participants of the EAAA Caregiver Survey, 66 (78%) identified as female and 18 (21%) identified as male. In terms of annual income, about 9.5% of respondents made under \$20,000 per year, 25% made between \$20,000 and \$40,000 per year, 21% made between \$40,000 and \$60,000 per year, and 41% made over \$60,000 per year (Figure 1).



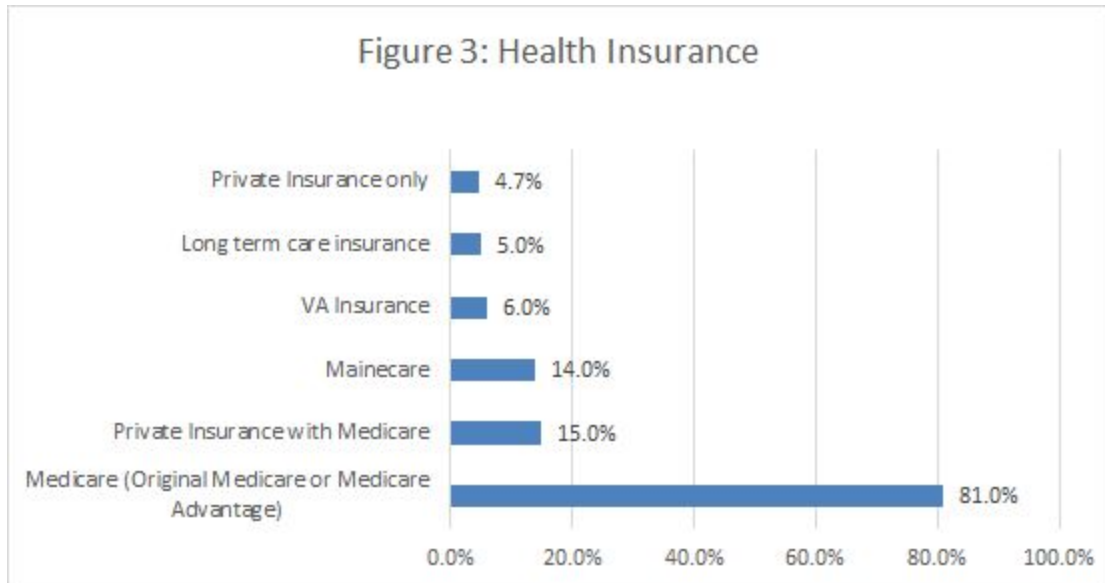
As indicated in Figure 2, nearly half (43%) of the survey respondents identified their relationship with the care recipient as a spouse or partner. About 27% identified as a son or daughter, and 19% of respondents identified themselves as a birth or adoptive parent to the care recipient. Of the 10% who claimed another relationship with the care recipient, some were professional caregivers, and others held other familial relationships such as sibling, aunt or uncle, or a parent-in law.



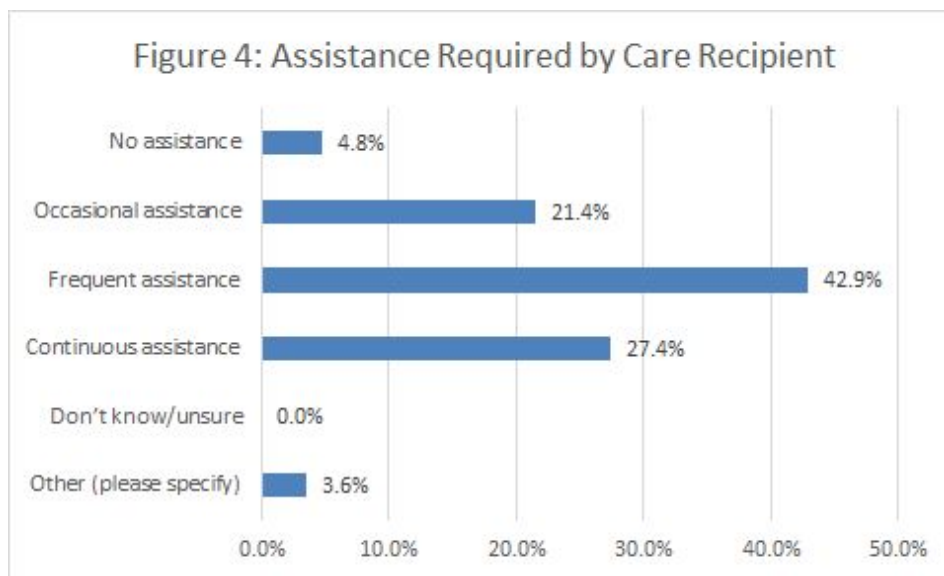
The care recipients were split between male and female, with 52% reported by their caregivers as female and 48% reported as male. When asked if the care recipient had an Alzheimer’s diagnosis, 61% of caregivers indicated that the care recipient did have an Alzheimer’s diagnosis and 39% indicated that their care recipient did not.

For insurance, most care recipients utilized Medicare (81%). Some care recipients accessed MaineCare (14%) or VA insurance (6%), either alone or with Medicare. A few had

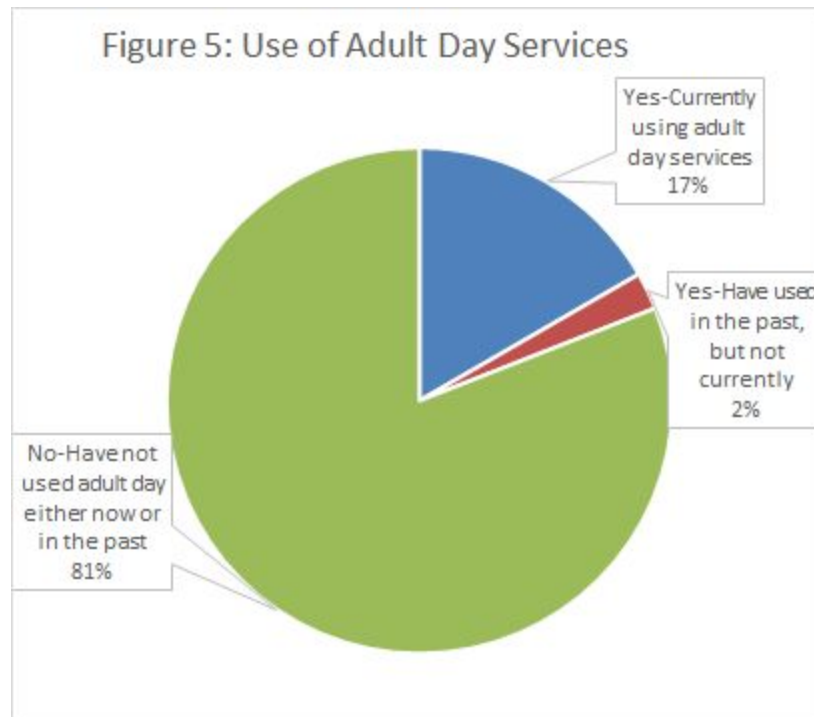
private insurance either alone (4.7%) or with Medicare (15%). A small number had long-term care insurance (5%). Insurance coverage among survey respondents is represented in Figure 3.



The vast majority of caregivers (92%) shared that their care recipient requires at least occasional assistance (Figure 4). Nearly half (43%) indicated a need for frequent assistance, with a quarter (27%) requiring continuous assistance. Taking medication as prescribed was the most common task (40%) that care recipients reportedly had “much difficulty” with. About a quarter (27%) of caregivers indicated their care recipient had much difficulty bathing and handwashing, and 20% had much difficulty with communication such as speaking and hearing.

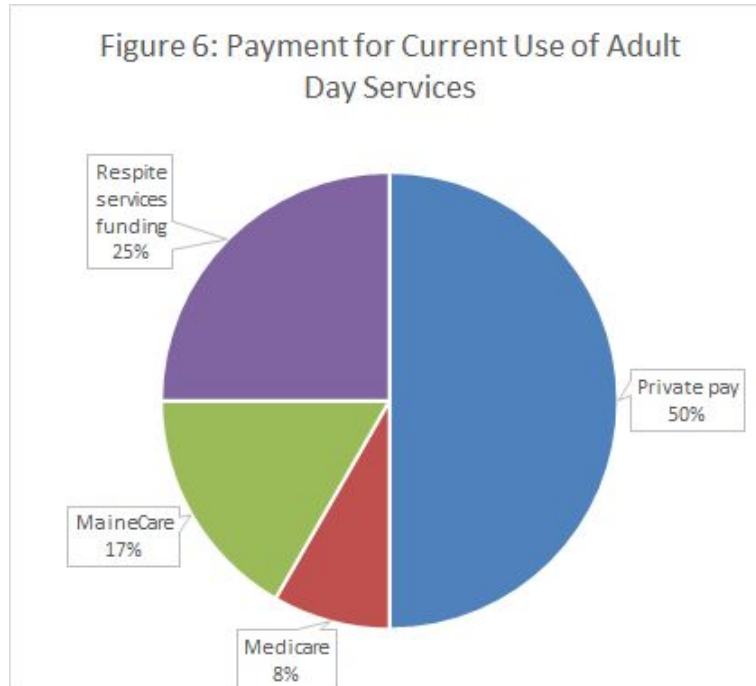


The majority of surveyed caregivers (81%) had not used adult day services in the past (Figure 5). A remaining 17% currently used adult day services, with only 2% having used these services in the past but not currently. Out of those respondents who currently used adult day services, all indicated that their needs were at least sometimes met, with two-thirds sharing that they were “often” met.

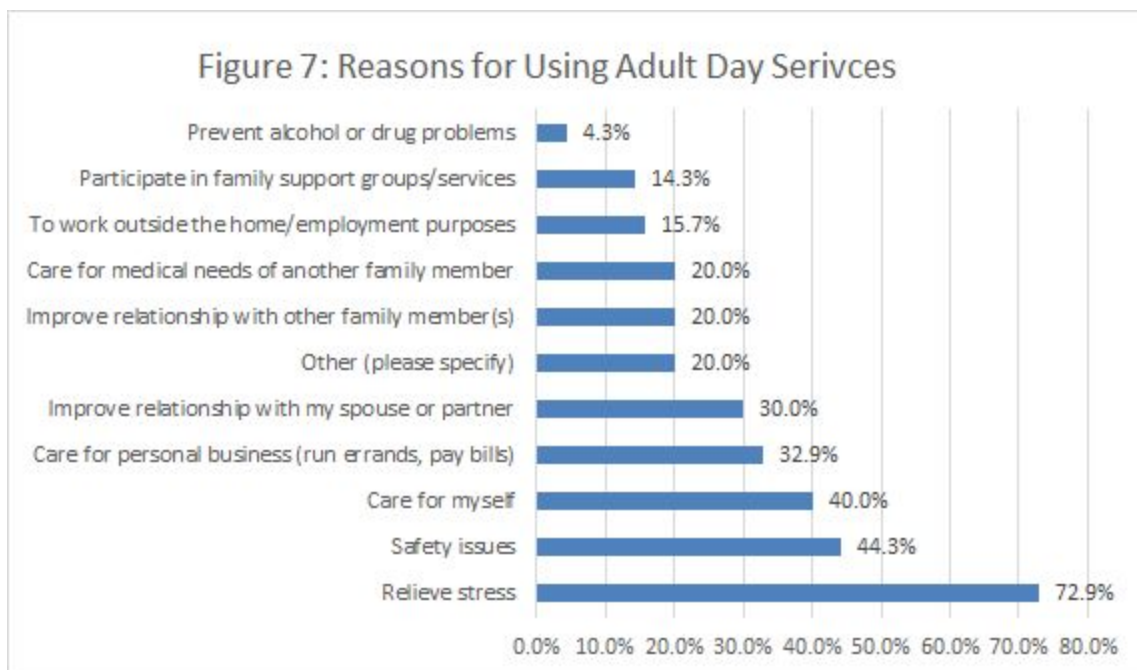


Out of the listed options in the survey, the biggest barriers for those participants who had not used adult day services before were the cost of services (20%) and not knowing that such services existed (20%). Nearly a quarter (23%) said they did not use services because they were happy with their current arrangement. A large proportion of respondents (40%) wrote in other responses. The majority of these comments indicated that the care recipient either did not need adult day services yet, or had too many care needs for these services/were already living in a professional care environment. The other common theme was that the caregiver felt that the care recipient would not consent or be interested in attending adult day services.

People who were using ADS paid for the services in a number of ways, with over half using private funds. While 7 respondents indicated that they paid for ADS with Medicare, we believe they may be confused about this as Medicare does not generally pay for ADS programs. Payment for ADS is shown below, in Figure 6.

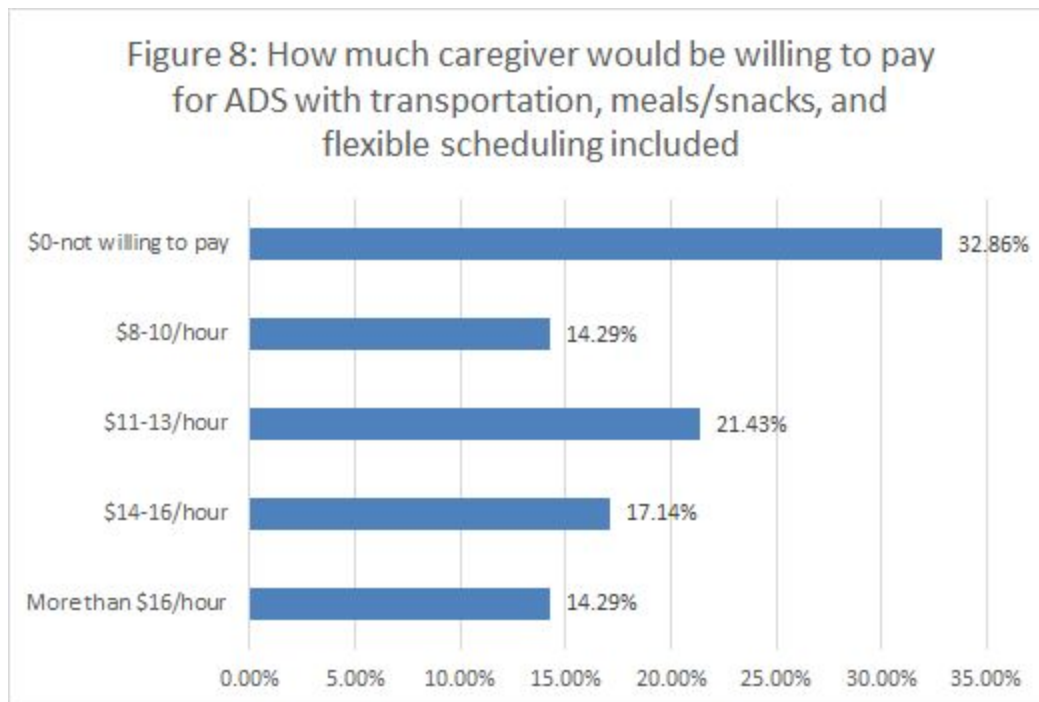


When asked what events would or did lead the survey participants to use ADS, the majority of respondents indicated they would use them to relieve stress (72%) (Figure 7). In a similar theme, the two next most common choices were related to “safety issues” (44%) and to “care for myself” (40%). Some participants (20%) also wrote in a response, of which the most common theme was the desire for socialization for the care recipient. Another theme was giving the caregiver time to improve relationships and socialize with other family members or friends.



In terms of logistics, 70% of respondents indicated that they would use ADS two or more days per week, and weekday mornings and afternoons were the most popular times. According to the survey respondents, the most important features for a potential ADS program to have were flexible scheduling and provided meals, which were rated “important” by 32% and 26% of the respondents, respectively. “Activities with children” was rated “not important” by 54% of the respondents. This highlights that the priorities of caregivers may have more to do with the concrete aspects of services, such as timing and meals, rather than the specific programming offered by the services.

Payment stands out as a barrier for the caregivers surveyed, as demonstrated in Figure 8. About one-third of respondents indicated that they would not be willing to pay for ADS even if those services included transportation; transportation with meals & snacks; or transportation, meals & snacks, and flexible scheduling. However, of those respondents who were willing to pay, there was an increase in willingness to pay \$11-\$16+/hour as the services offered increased. Regarding administration of medications, 63% of caregiver respondents indicated that administration of medications was not needed, 23% would be willing to pay extra for the administration of medication, and 14% would need medications administered but would not be able to pay extra. Although that is only 14% of the total group, it represents 38% of the participating caregivers who would need medication to be administered at adult day services. Exploration of medication assistance was explored via the survey as it is a service that requires specifically trained staff and would need to be accounted for in program model planning.



Key Informant Interviews Findings

1. Challenges

One major theme emerging from the key informant interviews was the challenges that occur when running an ADS program. These challenges fall into the categories of financial challenges, marketing and combating the stigma around ADS, and creating a program that is appropriate and beneficial for all participants. The financial challenges are the most significant. In order to run ADS, an organization must have a building that meets licensing code standards, which may require substantial renovation of an existing structure or construction of a new building. Many services rely on at least some volunteers to staff the programs, but there must be funds for at least some paid staff such as an executive director and program and volunteer managers. With a health model, there is more need for paid staff as a nurse and social worker must be on contract. Funding an ADS program can be difficult as reimbursement levels for ADS are often not adequate to meet program costs. Even if a care recipient has insurance or state funding that covers ADS, it generally does not cover the real cost of care during a day in an ADS program. In addition, it is important for an ADS program to maintain a full census, but this can be a challenge, especially in a rural area where people may not have transportation to such services. Some services provide transportation, but this represents an added cost.

It became clear during these interviews that a) many potential ADS consumers may not be able to pay for such services and don't have insurance, or are not eligible for state funding, that would cover these services and b) reimbursement rates from insurances and state funding that do cover ADS are generally not high enough to cover the costs of running such a program. Difficulty maintaining a full census can amplify these issues. One way to raise funds and attract clients is through marketing and outreach efforts, which bring their own challenges. Adult day services are highly stigmatized both by care recipients and caregivers, who may view such services as institutional and custodial rather than providing active socialization and respite. Participants themselves are often resistant at first, but generally come to enjoy ADS programming with time. Because of the initial stigma related to ADS, marketing these programs can be very difficult.

The final challenge that was discussed throughout the interviews was creating activities that appeal to people with differing levels of impairment, and also finding activities that appeal to men. ADS best serves people who are moving from mild to moderate dementia, so it can be difficult to create activities that are appropriate and engaging for a group of people who may have very different needs and cognitive abilities. It is also possible that participants' individual levels of impairment change over time, creating a need for flexibility in activities and a heightened awareness and attunement among staff to the participants' needs on any given day.

2. Populations Best Served by ADS

According to the key informant interviews, the two groups that are generally best served by ADS are care recipients, or ADS clients, and caregivers. Care recipients who gain the most from ADS tend to be people who are progressing from mild to moderate dementia, who do not need continuous one-on-one care, and who are not incontinent. Key informants indicated that individuals who enjoy socializing with others and who would benefit from being around others who have dementia--as the cognitive transitions can bring on feelings of anxiety or loneliness that can be alleviated through group activities and connections--are also best served by ADS.

The caregiver populations best served by ADS tend to be those caregivers who are experiencing high levels of stress and need respite to take care of everyday activities such as grocery shopping or chores, or who need some time to see their own family and friends in order to feel emotionally supported. These feelings of stress or needing support often arise when the care recipient reaches a level of impairment restricting the caregiver's ability to leave the care recipient alone for stretches of time. Key informants also shared that many caregivers seek out ADS when they feel that the care recipient is isolated and would benefit from socialization that would ultimately make the care recipient happier at home.

3. Integrating Child Care Programs

Most key informants responded positively to the idea of incorporating child care programs into adult day services. The biggest benefit is that ADS participants tended to open up around children and engage with the activities. These programs work best when they are structured, time limited and don't involve too many children. There should also be a separate option available, as children can be noisy and depending on the needs of the clients, potentially too overstimulating. Intergenerational programming is easiest to accommodate when the groups volunteer to come themselves and prepare the activities or when the children can easily integrate into already planned activities. It is important to note that incorporating child care programming into ADS programming requires extra staff time, as it takes added effort to solicit participation from schools or other community groups. While intergenerational programming is experienced as a positive activity to include from time to time, it would potentially be costly and logistically challenging to implement on a regular basis.

4. Health vs. Social Model

ADS programs are generally classified into one of two categories: a health model and a social model. The ideal model is dependent on the community needs and intended client population of the ADS program. In the Bangor area specifically, there is already a thriving social model ADS program, My Friend's Place, which charges a low rate and is currently running at full capacity. Most key informants thought the health model would best meet the needs of those who would use the services locally, and would not compete with My Friend's Place. It is still

possible to restrict eligibility with a health model, if need be. While a health model would require more staff, there is also potentially more state funding available because it would be accessible to and serve people with specific health needs who thus qualify for ADS funding programs.

5. Funding issues

As discussed in the “Challenges” section of this assessment, funding issues are one of the main barriers to developing and running a successful ADS program. To establish an ADS program, key informants recommended that it is best to have a large capital campaign and either a sponsoring organization or strong buy-in from the local community. The importance of community support cannot be underestimated, as local organizations can provide funding, referrals, and help distribute information about the services. Interviewees shared that most programs run deficits, with sponsoring agencies eating the costs and/or subsidizing the program. One reason for this is that, as mentioned, reimbursement rates tend to be too low to pay for the actual costs of running a program, and while private pay fees do need to be high enough to meet costs, they still need to be low enough that clients and caregivers can afford them and must be lower than the cost of home care, in order to be attractive.

6. Services most important to include

Key informants shared a variety of services they thought would be most important to include in an ADS program. There were services specific to staffing and professional resources, including medication administration and recreational, occupational, and physical therapy staff, consultants, or interns. Suggestions of what to consider in structuring the program included providing lunch, installing showers (potentially only for emergencies, as they can use a lot of staff time), or providing transportation. For most programs, providing transportation is cost prohibitive, although there are some who depend on it to maintain census depending on the location of the program and the needs of the clients. There were a number of activities that stood out in the interviewees experience as being important to include, such as socialization activities, having routines that clients can depend on happening at a certain time every day, music programs, quiet spaces available, arts and crafts, children’s programs, activities that appeal specifically to men, and group or individual caregiver support. Some of these could be incorporated together, such as having a children’s chorus perform for the clients and maintaining a quiet space in a different room for those who may be uninterested or overwhelmed.

7. Community Need

When key informants commented on community need for ADS, their responses focused on caregiver need, care recipient need, and wider community opportunities. ADS services can

provide much needed respite for caregivers. Regular ADS can allow caregivers to maintain at least part-time employment, and benefits both caregivers and care recipients by forestalling institutionalization and providing care that is sometimes less expensive and more reliable than home care. For the care recipients, ADS can provide socialization for isolated elders which can benefit both emotional and physical health. For the community at large, having a local ADS program is an opportunity to bring together generations through children's programs or through student internship or volunteer placements.

8. Referrals/Marketing

Based on these interviews, it is clear that an important step in creating and sustaining a successful ADS program is a strong marketing campaign and referral system. Marketing can increase buy-in from local organizations and community members, and can educate the public about the realities of ADS beyond the stigma and misconceptions often associated with it. This can happen through public service announcements and/or communication with healthcare and social service providers about the window in disease progression when ADS would be most useful for their patients or clients. The connection with providers is also an important step in building a strong referral network, as they are often helping clients plan through changes in their cognitive impairment and can educate them about ADS, if relevant. Another important referral and marketing tool is word of mouth. If a program is successful and trusted, people in the community will refer services to each other. Southern Maine Agency on Aging, one of the organizations that participated in an interview, works to build this trust by providing the opportunity to participate on a trial basis for a day.

9. Volunteers

Some of the key informants interviewed have had great success relying on volunteers to fulfill their organization's mission. Using volunteers allows for more one-on-one attention than is possible with limited staff. Volunteers can take the lead on activities in their area of expertise, such as music, arts, or exercise. Volunteers are often passionate about what they do, and therefore may be less prone to burnout than paid staff. They are also potentially referral sources or spokespeople in the community, aiding in word of mouth recognition of the program. Considerations to keep in mind with volunteers are that they do have to be trained, and it can be difficult to find a source of reliable, consistent volunteers. This is easiest if program organizers have a known pool of community volunteers or a partnership organization to pull volunteers from.

Discussion

While the responses to the Caregiver Survey indicated a high level of insurance among care recipients, this does not necessarily translate into access to ADS. Only Medicaid, VA, and long-term care insurance have mechanisms for funding ADS, and frequently they include copays. The State has additional funding sources for medically and financially eligible individuals. Through the interviews with key informants, it is clear that even when insurance or state funding does cover some of the cost of ADS attendance, it is frequently not enough to cover the actual cost of running the program. Successful ADS programs are often begun with a large initial capital campaign, combined with strong community commitment and partnerships, which this team does not have the capacity to initiate or see through at this time.

While caregivers who use ADS are satisfied with their experiences, surveys and interviews indicated that there are many more caregivers and care recipients who may benefit from ADS but who do not know about it or who are not receptive to this care option. Meeting the needs of caregivers of Maine was also underscored in the recent State Plan on Aging (Maine DHHS, 2016), which noted that 66% of surveyed caregivers had given up things they enjoyed such as spending time with family and friends and over half said they had missed too much work because of their caregiving duties. This research reported on here further documents those unmet needs for family caregivers.

Regarding intergenerational programming, the Caregiver Survey did not demonstrate a specific desire for this kind of programming over others. Key informants were generally positive about intergenerational programming, but stressed that it must be planned and implemented carefully so as to avoid overwhelming clients and staff.

Conclusion and Next Steps

After conducting this Needs Assessment, the research team is better informed about the opportunities and challenges of developing an ADS program in the greater Bangor area. There is a need for such programming, but at this time, this team does not have the capacity to initiate a full ADS program. After analysis of the findings, the research team has decided the most prudent step would be to test a small-scale program. The Executive Director of EAAA, a participant of the research team, will trial the “Vigorous Minds” program in the fall of 2019. This program is similar to the Memory Joggers program currently offered by My Friend’s Place on Wednesdays from 10:00 am to 2:00 pm in Bangor. By offering the Vigorous Minds program on a different day, and initially at no cost to participants, EAAA will be able to assess community interest and begin to identify the resources that would be required to transition such programming into a full scale ADS program. We will continue to assess the capacity of the greater Bangor area to support an ADS program (in terms of the potential to raise substantial funds and community demand), with particular attention to the needs of individuals who do not have access to Medicaid (MaineCare), other state funding, VA, or long-term care insurance to pay for such services. We believe the pilot Vigorous Minds program will inform our continued interest in

creating an ADS program that is accessible to low-income and uninsured caregivers and care recipients in the greater Bangor area.

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Addendum A

Family Caregiver Survey about Adult Day Services

Eastern Area Agency on Aging is collecting feedback from caregivers like you about adult day services. Please take a moment to share your thoughts with us.

What are adult day services? Adult day services (ADS) is a professional care setting in which older adults, adults living with dementia, or adults living with disabilities participate in individualized and supervised social activities. This is sometimes called “adult day care.” My Friends Place and Friendship Cottage are examples of local adult day service programs.

1. What is your zip code? (Please write in) _____

2. What is your town? (Please write in) _____

3. What is your gender? (Circle one) Female Male

4. What is your annual household income? (Check one)

- Less than \$10,000 per year
- 10,000-\$20,000
- \$20,001-\$30,000
- \$30,001-\$40,000
- \$40,001-\$50,000
- \$50,001-\$60,000
- \$60,001-\$70,000
- \$70,001-\$80,000
- Over \$80,000 per year

5. Counting yourself, how many people are included in the household income above? (write-in): _____ people

6. Which best describes your relationship to your care recipient? (Check one)

- Birth or adoptive parent
- Foster parent
- Grandparent
- Spouse or partner
- Sibling
- Son or daughter
- Close friend
- Other (please explain):

7. What type of health insurance does your care recipient currently have? (Check all that apply)

- Medicare
- MaineCare
- VA Insurance
- Private Insurance (Medigap-Humana, Blue Cross, etc.)
- Long term care insurance
- Other (please explain):

8. What is the gender of your care recipient? (Circle one) Female Male

9. Does your care recipient have a diagnosis of Alzheimer’s or dementia? (Circle one)
 Yes No

10. How much assistance does your care recipient require? (Check one)

- No assistance
- Occasional assistance
- Frequent assistance
- Continuous assistance
- Don’t know/unsure
- Other (please explain):

11. How much difficulty does your care recipient have with each of the following?
 (✓ Check one box for each item)

Activity	No Difficulty	Some Difficulty	Much difficulty	Don’t know/Doesn’t apply
Communication (e.g. speaking, hearing)				
Feeding				
Dressing				
Bathing and handwashing				
Taking Medication as prescribe				
Other (please explain):				

12. Do you currently use adult day services or have you used such services in the past?
(Check one)

- Yes-Currently using adult day services (SKIP TO QUESTION 18)
- Yes-Have used in the past, but not currently
- No-Have not used adult day either now or the past

13. If you do not use adult day services currently, what prevents you from using such services? (Check all that apply)

- Cost
- Services are not available
- Location
- Transportation
- Hours of operation
- Happy with my current caregiving arrangements
- Other (Please explain):

14. What events would lead you to use adult day care services now or in the future?
(Check all that apply)

- Relieve stress
- Improve relationship with my spouse or partner
- Improve relationship with other family member(s)
- Care for myself
- Care for medical needs of another family member
- Safety issues
- Prevent alcohol or drug problems
- Care for personal business (run errands, pay bills)
- Participate in family support group/services
- Other (please explain):

15. If you were to use adult day services, how often would you need these services?
(Check one)

- Less than one day per week
- 1 day/week
- 2 days/week
- 3 or more days/week
- Other (please specify):

16. If you were to use adult day services, what hours of the day would you need these services? (Check all that apply)

- Mornings
- Afternoons
- Evenings
- Weekdays
- Weekends
- Other (please specify):

17. If you were to use adult day services, how important would the following features be to you? (✓ Check one box for each item)

Feature	Not important	Somewhat important	Neutral	Important	Very important
Transportation to pick up care recipient					
Meals provided					
Flexible scheduling					
Activities with children					
Assistance with medication					
Other (please explain):					

18. For this question, please review the following program models and rate how much you would be willing to pay for each model:

Model A: Adult day services with transportation provided

Model B: Adult day services with transportation and meals/snacks provided

Model C: Adult day services with transportation, meals/snacks, and flexible scheduling

18a. What is the most you would pay for Model A per hour? (Check one)

- \$0-not willing to pay
- \$8-10/hour
- \$11-13/hour
- \$14-16/hour
- More than \$16/hour

18b. What is the most you would pay for Model B per hour? (Check one)

- \$0-not willing to pay
- \$8-10/hour
- \$11-13/hour
- \$14-16/hour
- More than \$16/hour

18c. What is the most you would pay for Model C per hour? (Check one)

- \$0-not willing to pay
- \$8-10/hour
- \$11-13/hour
- \$14-16/hour
- More than \$16/hour

19. Please share any additional comments you have about adult day services here:

Addendum B

Questions to Direct Key Informant Interviews on Adult Day Services

1. How do caregivers understand what ADS means? How do they learn about the services?
2. At what moment do caregivers feel they need ADS? What are the precipitating factors?
 - a. When do you think ADS could most help a caregiver and/or care receiver even if they don't recognize the need?
3. How does a program overcome the reluctance of caregivers or care receivers to use the services?
4. [For those providing services] What is your experience with providing services to reluctant caregivers or care receivers? How do you successfully engage them?
5. What is the profile of someone who might be most successfully served by an ADS program?
 - a. [For those providing services] What is the profile of the people you have most successfully served
6. [For those who are running ADS programs] What lessons have you learned and what advice might you offer for a group planning to start a new ADS program?
 - a. What were some of your major challenges in implementing the program?
7. What are your thoughts/experiences about incorporating activities with children at an ADS program?
 - a. What is the profile of an older adult who is most likely to benefit from such programming?
8. What do you find people can/would pay for ADS?
9. What particular services do you think are necessary/preferable to potential caregivers/care receiver?
 - a. How important do you think it is to have assistance with medication management?

10. Do you know of others who are considering starting an ADS program in the greater Bangor area?

11. [For Dirigo Pines] Are you considering opening an ADS program? (next page)

- a. If so, who do you see as your primary clients?
- b. What services would you provide?