

Adult Day Services in Iowa
Strengthening a Critical Home and Community-Based Service

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Table of Contents

Introduction	5
Data Collection Methods	6
Data Analysis	8
Results	8
Terminology	8
Program and facility description	9
Client Description	11
Barriers related to Expansion of ADS	11
Program costs and funding sources	17
Funding barriers	20
Adequacy of third party reimbursements	22
Iowa Code and Administrative Rules	22
Technical assistance and support	24
Opportunities for Growth	26
Summary and Recommendations	27
Appendices:	
A: Location of Iowa ADS programs	31
B: Survey of ADS providers	33
C: Recruitment fliers for focus groups	39
D: Semi-structure interview guide for focus groups	42
E: Unit cost analysis	45

Adult Day Services in Iowa: Strengthening a Critical Home and Community-Based Service

With the growing cost of long-term care, there has been an increased interest in strengthening the home and community-based service system nationally and in Iowa. Home and community-based services are the least-restrictive type of service within the continuum of care for older adults and individuals with various disabilities. They are designed to provide services to individuals that will assist them in remaining at home rather than moving to long-term care facilities. As individuals are increasingly invested in remaining at home or with their caregivers, home and community-based services are frequently identified as the most attractive care option. Additionally, home and community-based services are a great cost-saving resource for state Medicaid dollars that are often used to pay for long-term care.

Adult day service (ADS), also referred to as “adult day health services” and “adult day care”, is one home and community-based service designed for older adults with complex physical and cognitive health conditions and younger individuals (18+ years old) with a variety of physical, cognitive, and developmental disabilities. This service provides participants with cognitive stimulation and socialization, as well as some medical care and assistance with activities of daily living, particularly bathing and toileting. The purpose of ADS is two-fold: 1) Keep older adults and those with disabilities out of institutional settings and in the community with friends and family for as long as possible; and 2) Provide support and respite to caregivers.

The State of Iowa Code defines ADS as “organized programs providing a variety of health-related care, social services, and other related support services for 16 hours or less in a 24 hour period, to two or more persons with a functional impairment on a regularly scheduled contractual basis” (Iowa Code 231D and Iowa Administrative Code 321, Chapter 24). Presently there are 38 ADS programs in Iowa that meet this criteria. There are two primary program models for the delivery of ADS: medical and social. The *medical* model provides rehabilitative services, such as physical, occupational, speech, and hearing therapies, whereas the *social* model emphasizes social activities, maintenance of client functioning, nutrition and recreation. In Iowa, a majority of ADS programs offer a combination of these two models.

Compared to other home and community-based services, such as home health care or chore services, ADS has not received as much attention within the practice, research, or policy arenas. To better understand the status of this service across the country, the Wake Forest University School of Medicine’s Partners in Caregiving Program, with funding from the Robert Wood Johnson Foundation, conducted a nation-wide inquiry into the structure and utilization of ADS in 2001.¹ Nationally, and in Iowa, ADS was identified as an underutilized service. At the time of the study, there were 3407 ADS providers in the United States, with an estimated 5415 more needed nation-wide. At that time, Iowa had 83 facilities providing ADS, serving an estimated 1200 clients in 51 of the 99 counties. Whereas most states had a system of regulation and state oversight in place when Wake Forest conducted their study, Iowa had no regulations. It was not until 2004, with increasing pressure nationally and by state funding agencies for ADS to become regulated, that the Iowa legislature adopted legislation that mandated all ADS providers to meet certain core standards and to be certified by the Iowa Department of Inspection and Appeals (DIA). Subsequent to the requirements, 45 of the existing ADS programs ceased providing ADS for various reasons, including closing the program and deciding to only provide respite care. Currently, there are 38 certified and regulated ADS programs in 27 of the 99 counties in Iowa. The map in Appendix A identifies the location of each of these programs.

Even though ADS has been identified as a cost-effective service for older adults and people with disabilities, the expansion of ADS has been slow to occur, with some suggesting that the growth of ADS in Iowa has stopped. To better understand the reasons for the lack of expansion of ADS in Iowa, the Department of Elder Affairs (DEA) contracted with the authors at the University of Iowa School of Social Work to conduct an evaluation of the ADS system. This evaluation, conducted between January 1 and June 30, 2007, sought to assess the present needs and potential capacity of ADS in this primarily rural state. To this end, the evaluation team collected information from caregivers and ADS consumers, ADS providers, executive directors of the Area Agencies on Aging (AAA), executive directors of professional trade associations, community-based health and social service professionals, and personnel from the Department of Elder Affairs about 1) the barriers to expansion of ADS in Iowa; 2) the effect of current laws and regulations on providing ADS; 3) the adequacy and availability of reimbursement for ADS; and 4) the opportunities for growth of ADS in Iowa.

This report details the data collection methods used, summarizes the responses received from all participants, and provides recommendations based upon this data.

Data Collection Methods

Data were collected from a number of sources using research methods designed to gather the most accurate information from each group of respondents, including *surveys*, *interviews*, and *focus groups*. The participants included: Caregivers and ADS consumers, ADS providers, executive directors of the AAA's, executive directors of professional trade associations, other community-based health and social service professionals, and personnel from the Department of Elder Affairs. In addition, informational sources about ADS funding sources were reviewed. All research methods were reviewed and approved by the University of Iowa, Institutional Review Board (IRB) to ensure the protection of all participants.

Survey

ADS providers, as identified by the DIA, were contacted to verify their status as an organization, determine if they were presently providing ADS, and obtain the name of the administrator and mailing address. Surveys (see Appendix B) were mailed to the ADS administrators² to gather detailed information about each ADS service in Iowa, including their client base, funding and reimbursement sources, and technical assistance needs. Follow-up calls were made every two weeks for six weeks to providers who had not returned their survey to encourage their participation. Twenty-eight (74%) of the 38 ADS providers returned their surveys. Phone calls revealed that the primary reason ADS providers did not return the survey was that they "did not have time to fill it out." One survey was completed over the phone at the administrator's request.

Interviews

All ADS administrators who returned a survey were invited to participate in a telephone interview to obtain additional information about their ADS program, including the history of their organization, details on their funding and reimbursements streams, views of ADS regulations, and technical assistance needs. All but three of the administrators who returned the survey (n=25) completed the telephone interview.

Personnel from the Department of Elder Affairs participated in a two hour in-person interview about the history of ADS in Iowa and issues related to developing this program across the state. Executive directors from professional trade associations were contacted and asked to participate in a one hour telephone interview about their impressions of and involvement with ADS. Executive directors and staff from the Iowa Health Care Association, Iowa Association of Homes and Services for the Aging, and Iowa Association of Area Agencies on Aging agreed to participate. The board president for the Iowa Adult Day Services Association (IADSA) also participated. The Iowa Assisted Living Association and the Iowa Caregivers Association did not respond to several phone invitations to participate. A professional

employed at AARP contacted the evaluation team and requested the opportunity to participate in an interview about the history of ADS in Iowa and nationally; this interview is included in the results. Executive directors from each AAA were invited to participate in a one hour telephone interview about their views of the ADS system and the relationship between the AAA and ADS. Executive directors, together with any key staff, particularly coordinators of case management and funding contracts, from 12 of the 13 Iowa AAAs participated in a one hour telephone interview. One AAA director did not respond to numerous telephone messages or personal letters about participating in the evaluation.

Focus Groups

Focus groups were conducted in different regions of the state to understand ADS from the perspective of health and social service professionals and familial caregivers. Focus groups were conducted in Decorah (AAA area 1), Sioux City (AAA area 4), Iowa City (AAA area 10), Des Moines (AAA area 11), Creston (AAA area 14), Ottumwa (AAA area 15), and Burlington (AAA area 16). These areas were selected based on their geographic location, population, and the status of ADS in the area. Table 1 summarizes the characteristics of these areas and the number of participants in each location.

Table 1: Focus group locations and number of participants

Location of Focus Group	Population of county	AAA region	Location in state	ADS Providers in AAA area	Professionals/ Caregivers
Burlington	25001-99000	Area 16	South East	0	14/1
Creston	25000-under	Area 14	South West	0	4/2
Decorah	25000-under	Area 1	North East	1	8/7*
Des Moines	200000-over	Area 11	Central	9	17/2
Iowa City	100000-200000	Area 10	East Central	6	17/2
Ottumwa	25001-99000	Area 15	South Central	2	8/0
Sioux City	100000-200000	Area 4	North West	2	8/1

* Two of these participants were former caregivers and present consumers of ADS programs.

To identify potential focus group participants, fliers (see Appendix C) were distributed to professionals and family caregivers within each service area. Professionals invited to participate were identified through AAA databases and community resource guides, such as the I4A website, and represented the following services: ADS, AAA, home health care and private duty, long-term care facilities (independent living, assisted living, and nursing home), hospice care, hospital geriatric psychiatry and discharge planners, community transportation services, Alzheimer’s Associations, and other non-profit healthcare or aging-related associations. Two weeks following the distribution of the fliers, a research assistant contacted each professional via telephone to request their participation in the focus group. The focus groups lasted approximately 90 minutes. Appendix D provides a copy of the semi-structured focus group guide.

To protect the confidentiality of clients and their caregivers, AAA staff and all invited community professionals were asked to distribute fliers to appropriate caregivers. Caregivers were encouraged to

contact an evaluation team member if they had any questions and to register to participate in the group. The caregiver focus groups lasted approximately 60 minutes.

Although a large number of caregivers and consumers were invited to attend the focus groups, few caregivers were able to arrange respite care and/or transportation to the focus group site, hence they were unable to attend. Other caregivers were not able to leave their employment to attend the group. Some caregivers reported that they were not able to attend the focus group, but were willing to talk with the evaluators about their experiences. In these cases, the caregivers were interviewed via the telephone to ensure their experiences would be included in this report. These interviews lasted between 20-30 minutes. In the future, alternative methods must be used to gather input from caregivers about ADS programs.

Background Data

Literature searches were conducted to gather information about each funding stream for ADS. Telephone interviews were conducted with the Department of Veteran Affairs, Department of Human Services, Department of Elder Affairs, AAA, and long-term care insurance providers to obtain additional information on funding and reimbursement sources for ADS.

Data Analysis

This evaluation collected both quantitative and qualitative data. Quantitative data from the surveys were stored in and analyzed using the Statistical Package for the Social Sciences (SPSS, v14). Frequencies and other descriptive statistics were generated and then confirmed by a second evaluator.

Transcripts from the interviews and focus groups were analyzed independently by the co-evaluators using line by line coding.³ Line by line coding entails reading the transcriptions without a priori codes to determine critical meaning units within the data. The meaning units were then grouped into common categorical areas. The categories produced by each evaluator were compared to ensure reliability within the findings for this evaluation. The categories were then grouped into common thematic groups. The final grouping of themes and quantitative results were also reviewed by the project research assistants to ensure consistency in evaluation and as a further test of accuracy, trustworthiness of the analyses, and reliability.

Results

Across the state, the need for ADS services was recognized by the respondents in this study. Due to the lack of ADS / respite services in many rural communities, it was reported that dependent elders and those with disabilities continue to be placed in unsafe situations. For example, many caregivers and professionals shared stories of elders sitting in caregivers' cars during the winter while caregivers worked because of the lack of services. Another participant reported that an elder spent days lying on the floor, unable to call for assistance, waiting for the private duty aide to come for her weekly visit. There was an equal recognition of many barriers that presently limit the availability and viability of ADS programs. These are discussed in detail below. Overall, ADS programs were not well known or understood by community professionals or caregivers attending the focus groups, as the majority of participants, both professional and caregivers, in four of the six groups indicated that their primary reason for attending was to learn about ADS.

Terminology

Based upon the responses of study participants, it was apparent that professionals and caregivers in Iowa remain confused about the terms "respite" and "adult day service" and what services should be provided by each. Caregivers reported that they often did not know what to call the service they wanted the care

recipient to attend until a professional told them a name. Community professionals sometimes referred to ADS as “respite” because it provided caregivers with time away from their caregiving duties. Professionals from long-term care facilities reported that they *could* provide ADS when questioned about the services offered by their facility. However, when ADS regulations were discussed, they quickly used the word “respite” instead of ADS, but noted that they did not see a real difference between the two services. Professionals, who were not familiar with the ADS language in the Iowa Code, were more likely to use the terms interchangeably. Additionally, there was great confusion regarding the regulations for respite care services versus ADS. In this report, ADS refers to the service defined in the Iowa Code.

Program and Facility Description

This description of the existing ADS programs in Iowa was compiled from completed surveys (n=28) and administrator interviews (n=25). Not all percentages reported equal 100% due to missing data from ADS providers.

All but two of the programs identified themselves as non-profit organizations (92%, n=26); one was for-profit and the other was government-based. Eighty-six percent of programs (n=24) were operating under the auspices of a parent organization, such as a long-term care facility, retirement community, or county-wide aging services provider. Whether or not a program belonged to a parent organization often determined the amount of control and decision making ability that the administrators’ possessed and the amount of knowledge that they had about the budgets, reimbursement sources, and funding for their service. While all of the programs were Iowa DIA certified, eight (29%) of the programs were also accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF), a national accreditation program. The majority of the programs (n=18, 64%) provided a combination of social and medical services. The remaining ten providers (36%) identified their program as “social” only.

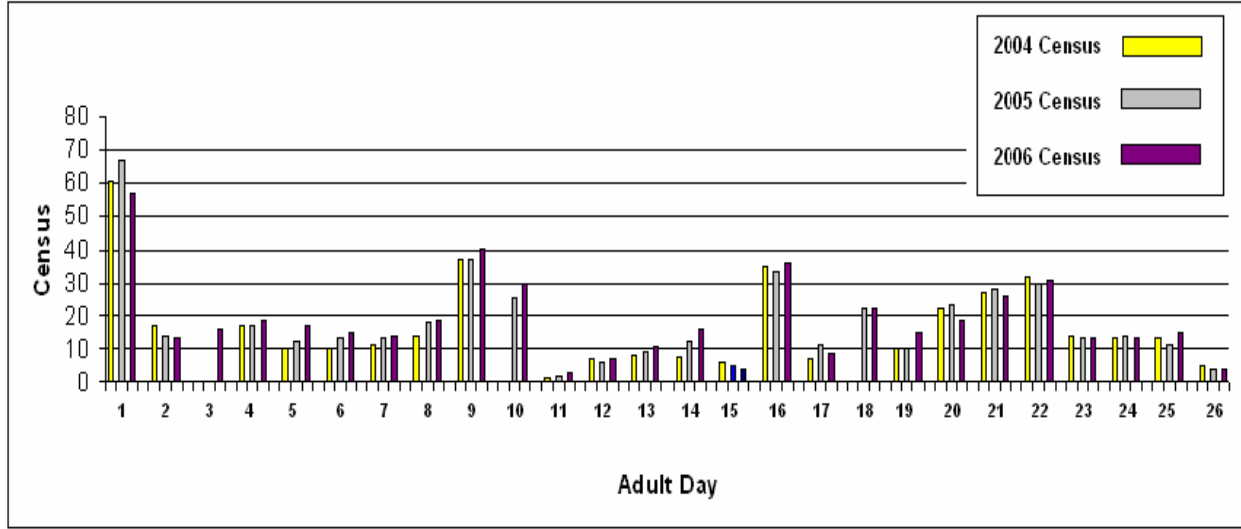
Programs reported linkages to professional organizations that supported their service delivery. Seventy-seven percent of the programs (n=22) belonged to the Iowa Adult Day Service Association (IADSA), while approximately one-third (33%) of the programs belonged to the National Adult Day Service Association. Three respondents were unaware of IADSA.

The majority of the programs (89%, n=25) were open 5 days per week and most programs (71%, n=20) were open for at least 8 hours per day. To meet the needs of their clients, programs employed between 2 and 12 staff, both part and full-time, who possessed certified nursing, activities, or registered nursing degrees. Few facilities employed a full-time social worker or someone to work specifically with families. The ADS providers on average maintained a 2:6 staff to client ratio.

Some ADS programs were targeted to specific populations. Fifty-four percent (n=15) of the ADS programs served primarily older adults or those with some form of dementia; 11% (n=3) served only individuals with mental retardation or other developmental disability. Twenty-five percent of ADS programs (n=7) provided services to older adults and those with various disabilities.

While some of the ADS programs were small, with the ability to serve between 6 and 20 clients (n = 9, 32%), most (n = 14, 50%) were mid-size with the ability to serve between 21 and 40 clients. Three programs (11%) were able to serve up to 65 clients (according to 2007 capacity projections). Most programs had experienced a slight increase in the number of clients served over the past three years and in their average daily census. Figure 1 illustrates the growth in the number of clients served by each program between 2004 and 2006.

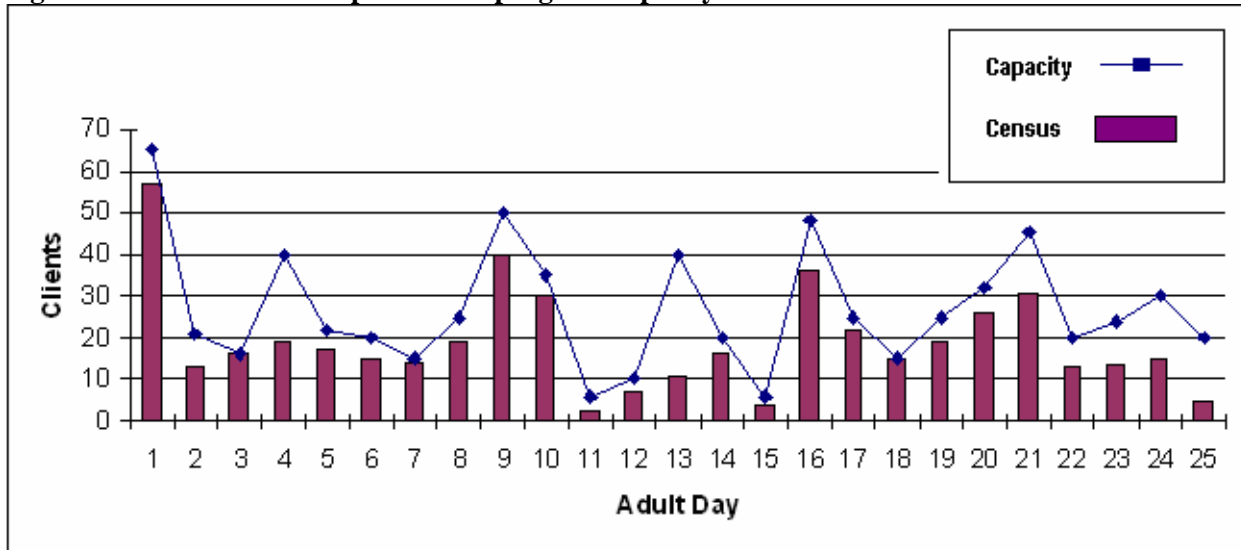
Figure 1: ADS census 2004 – 2006



*Chart only includes complete data

Based on 2006 ADS census data, only three programs were operating at or very near capacity as shown in Figure 2. Overall, programs were operating at approximately 70% of their total capacity in 2006, which had improved from both 2004 (60%) and 2005 (64%).

Figure 2: Client census compared with program capacity in 2006



* Chart only includes complete data

As seen in Appendix A, the majority of ADS programs exist in the central part (AAA area 11) and the eastern part (AAA areas 8, 9, and 10) of the state. In other locations of the state, such as the western and northern counties, ADS programs exist, but are scattered throughout the area. This is complicated by the vast geographic distance between communities. In the southwestern and northwestern (AAA areas 3, 13, 14), as well as southeastern and northeastern (AAA areas 1, 16) parts of Iowa, ADS is not available to individuals who could benefit from the service.

Client Description

Clients ranged in age from 16 to over 100 across the programs, with younger clients averaging 37 years of age and older clients averaging 89 years of age. Some programs reported that they served high school age clients with disabilities over the summer months when schools were not in session. Table 2 provides general characteristics of the clients served in Iowa ADS programs and the reasons for their attendance.

Table 2: ADS program client characteristics

Client characteristics	Average	Range
Age		16-106
Youngest	37	16-65
Oldest	89	20-106
Gender		
Male	41%	
Female	59%	
Reason for attending		
Dementia	44%	
Mental illness	18%	
Physical health	36%	
Developmental disabilities	34%	

* Some clients were attending for multiple reasons

Barriers Related to the Expansion of Adult Day Services

Data from the Department of Elder Affairs, professional trade associations, AAAs, community focus groups consisting of professionals and caregivers, and ADS providers identified multiple barriers to the current ADS system and for the future expansion of the service in Iowa. The discussion of barriers below is divided into systemic, community, and funding barriers. Tables 3, 4 and 7, below, summarize the barriers that were identified by each respondent group. It should be noted that many barriers were identified by both urban and rural professionals and caregivers, but the implications of some barriers differed depending upon geographic location. Examples of these differences are discussed below.

Systemic Barriers Systemic barriers pertain to having a sufficient infrastructure to support the growth of ADS. Participants identified systemic barriers that were endemic across the state, for example, transportation and funding, and others that were present within the ADS network in Iowa.

The primary barrier, *transportation*, was identified by all data sources. There was a consensus that the transportation system in Iowa is neither accessible nor affordable for older adults and those who may be interested in using ADS. ADS programs that were not able to provide transportation or had a limited transportation service saw this as a major factor reducing the utilization of their service. Community

professionals reported that due to limited transportation, they often would not refer potential clients to ADS programs given the additional stress and burden that transporting the care recipient would cause for the caregiver. This was particularly seen in rural communities where it may have taken an individual over an hour to get to the community that housed the ADS. In urban settings, public transportation may have been available, but not appropriate for the type of client using the ADS. As stated by one individual, “People...would be on the bus for an hour to an hour and a half to get there and an hour to an hour and a half to get home and so if you’ve got a dementia person, you are asking for trouble.”

Funding was the second most commonly identified systemic barrier. Across respondents, poor funding and reimbursement for ADS was identified as severely limiting the growth and expansion of the service. Statements, such as “Raise the reimbursement rate to actually cover our costs,” “If the State would at least reimburse us for what we do that would help,” or “I wish that legislators could realize that the money that they could put up front to start off and help a program get going could make such a difference in how much money they have to put out over the course of how many years” exemplified the views of the participants.

The *lack of political clout of ADS* compared to other services, notably nursing homes and assisted living, was commonly identified as a barrier to the expansion of ADS. ADS providers indicated that they had “no voice at the political table.” A commonly expressed example of the limited political voice of ADS was that the state regulations for ADS certification were thought to too closely mirror assisted living regulations, thus devaluing the unique attributes of ADS programs. People believed that if ADS had political clout when the regulations were developed, the components of the regulations would have reflected the uniqueness of their service. Respondents did not believe that the political voice of ADS providers has increased over time.

The *value-base of older adults in Iowa* was identified as another systemic barrier. It was widely expressed that older adults feel stigmatized by needing additional assistance, which is a by-product of the values of rural communities. Although the stigma of needing ADS was also noted by some urban providers, the perception that in rural communities “everyone knows what everyone else does” enhanced the stigma felt by ADS consumers and their caregivers in those communities. As a result, many respondents expressed that elders and their caregivers do not explore ADS (when available) until there is a health crisis by either the caregiver or potential consumer requiring the use of a long-term care facility, at which time ADS may no longer be an appropriate option.

Finally, the *Iowa Adult Day Service Association (IADSA)* was identified as a systemic barrier, which was not assisting in the growth of the ADS industry. IADSA, as an organization, is still in the infancy stage of organizational development. Without a website and paid staff, respondents identified that the association struggles to communicate pertinent ADS information with its members in a timely fashion. Additionally, members indicated that in its current form, IADSA does not have the infrastructure to organize lobbying efforts, conduct leadership and service trainings, or assist with the development of new programs. The primary challenge to this organization is that administrators from ADS programs serve as the president of the organization on a rotating basis, in addition to managing their own ADS program.

Table 3, below, summarizes the systemic barriers and identifies each of the respondent groups that recognized each barrier.

Table 3: Systemic barriers and respondent groups identifying each barrier

Systemic Barriers	Respondents					
	DEA	Professional Trade Associations	AAA	ADS	Community Professionals	Caregivers
Transportation	✓	✓	✓	✓	✓	✓
Adequate funding	✓	✓	✓	✓	✓	
Policy / Regulations	✓	✓	✓	✓	✓	
Lack of legislative support	✓	✓	✓	✓		
Strong nursing home lobby	✓	✓	✓			
Lack of political clout of Iowa ADS Association	✓	✓		✓		
Legislators not recognizing cost-effectiveness of community-based services	✓		✓	✓	✓	
ADS regulations too closely geared to assisted living		✓		✓	✓	
Iowa Culture		✓		✓	✓	
Stigma of ADS		✓	✓	✓	✓	
Values of rural states			✓	✓	✓	✓
Program networks			✓	✓	✓	✓
Strength of Iowa ADS Association	✓	✓		✓		

Community barriers There were many community-level barriers identified by participants that also inhibit the growth of ADS in Iowa. While there is some overlap between systemic and community barriers, respondents believed that each of the barriers identified had specific implications for their own communities that were unique from the barriers noted at the systemic level.

A lack of community support was frequently identified by professionals and ADS providers as a primary barrier to ADS programs. They noted that key referrals sources, including the AAA, hospital discharge planners, and home health agencies, did not refer people to ADS when the service was available and accessible in communities, despite marketing and outreach activities. Professionals often had limited knowledge about ADS and the services that it could provide to clients. Professionals, who were familiar with ADS, but resided in areas of the state without an ADS program, saw the implementation of the

service as an “impossible feat”, due to the “extensive regulations” and lack of funding to start the program. This was particularly true in rural areas with county populations of less than 100, 000. Overall, ADS administrators reported that their regional AAA typically did not have the time, interest, or expertise to support the development of ADS in their area. This belief was confirmed by AAA executive directors. There were two exceptions: one rural ADS had received extensive technical assistance from the AAA which supported them to become a viable program and a second AAA that had invested a large amount of time in coordinating a feasibility study to determine the viability of ADS in their area.

Additionally, it was expressed that most rural communities *did not have the ability to financially support an ADS* unless it could be incorporated into a local nursing home due to the *limited numbers* of people who would use the service. Without the base of large corporations or foundations that are found in urban areas and together with the fact that all non-profit entities request funding from the same sources, respondents from rural areas believed that a substantial amount of money could not be raised to start and sustain an ADS. This sentiment was shared particularly among communities who previously had an ADS, but the facility had closed due to financial reasons. There was only one ADS in a rural community that was the exception to this pattern. ADS programs in rural communities expressed frustration at the lack of financial support that they received from the community and questioned if there was or would be in the future a substantial population of clients to help them growth the program to full capacity.

Participants representing rural communities identified a number of geographical challenges in providing ADS programs. *Transportation and distance people must travel* for services were most frequently identified. While transportation was recognized as a large systemic issues within the state, each community directly felt the impact of this barrier. Rural communities also strongly believed that the ADS model prescribed by the Iowa Code was a “urban” model that was not conducive to providing ADS in a rural setting. This issue is discussed in greater detail below. There was also concern that many rural communities in Iowa do not have a large enough population to support an ADS. While it may be assumed that people from neighboring communities could also participate in an ADS service, it was indicated that the lack of rural transportation prevented this from occurring.

Another key barrier to the expansion of ADS was *competition between providers*. In smaller communities, it was not unusual for one or two *nursing homes to play a critical role* in determining the feasibility of providing ADS. Given the limited client base in these communities, nursing homes reportedly were able to discouraged the development of ADS by encouraging potential clients to use their existing service. Some nursing homes did not believe it was economically feasible to add ADS programs within their existing structure. The *growth of assisted living* in Iowa was also identified as one of the greatest threats to home and community-based services. This was critical for ADS providers who expressed that potential private pay clients often chose assisted living instead of ADS for assistance. As stated by one respondent, “People that have lots of money are probably going to be pricing assisted living. That’s where the money people go and so that their loved one has 24 hour care and they don’t have to be the caregiver per say. They can be the daughter again or the spouse again by visiting the assisted living.” Many providers also expressed concern that *finding qualified staff*, especially in rural communities, was difficult. It was feared that potential ADS staff were more likely to seek employment in other health care settings where salaries and benefits may be better.

Finally, even though ADS has been identified as a program that can serve a large age range of individuals with multiple cognitive and physical conditions, providers felt that *older adults and individuals with disabilities do not want to attend the same program*. This theme was particularly shared by ADS consumers, as well as caregivers, as one of the drawbacks of having a care recipient participate in ADS. It was stated, “I don’t think the populations like to mix. I did have a nurse call me and say ‘Do you think you could take an elderly gentleman?’ In talking with this gentleman he realizes that my other client here

had developmental disabilities and he doesn't want to be lumped into that. Nor do my developmental disabled individuals feel comfortable around the elderly.”

Community professionals universally believed that the current cohort of older adults do not view themselves as “old” but as staunchly independent and “too proud” to accept any type of support. Thus, current elders are reluctant to use ADS even when it is clearly needed for themselves or to support the care recipient. Caregivers typically feel obligated to personally care for their parent or family member to be a “good” daughter or son. It was believed by participants that the next and succeeding generation of elders would be more likely to use community support programs. The following table summarized the community barriers and identifies the respondent groups identifying each barrier.

Table 4: Community level barriers and participant groups identifying each barrier

Community Barriers	Respondents					
	DEA	Professional Trade Associations	AAA	ADS	Community Professionals	Caregivers
Support and resources						
Limited community and AAA support of ADS	✓	✓	✓	✓	✓	
Inability of community to financially support ADS			✓	✓	✓	
Limited knowledge of ADS among potential referral sources	✓	✓	✓	✓	✓	
Clients referred to ADS too late				✓	✓	
Lack of service for “next generation” of older adults			✓	✓	✓	
Geographical challenges						
Accessible, affordable community transportation			✓	✓	✓	
Geographic distance for people to travel to ADS			✓	✓	✓	✓
Rural community viewing current ADS system as an “urban model”			✓	✓	✓	✓
Rural communities have limited population base to support ADS			✓	✓	✓	✓
Other service providers						
Growth of assisted living		✓	✓	✓	✓	
Competition between providers			✓	✓	✓	
Lack of qualified staff interested in ADS				✓	✓	
Values about who accesses services						
Older adults/disability clients not wanting to mix			✓	✓	✓	✓

Underlying both the systemic and the community-level barriers was *the lack of time* that the ADS administrators have to work proactively to address the above mentioned barriers to their program. It was not unusual for the administrator to be performing a variety of duties at the ADS, including cooking, programming, nursing, family support/social services, personal cares, such as bathing, and providing transportation -- or as one respondent described it, “making pea salad”. As stated by one ADS administrator, “I am the director, I am also the social worker, I am the marketer, and I am the fundraiser, and I report to the board, and I also oversee the volunteers.” These additional duties, which *could* be performed by other staff, removed the administrators from the roles that would assist in growing their businesses, such as marketing, public relations, continuing education and training, lobbying, and building community and statewide networks within the larger continuum of care for older adults and those with disabilities. Due to poor funding and reimbursements, which will be discussed below, ADS providers have few dollars available to hire additional staff; thus, these extra burdens rest on the administrators’ shoulders.

Program Costs and Funding Sources

Programs reported the cost for a client to attend ADS for a full day ranged from \$36 to \$64 dollars, plus additional costs for transportation and personal care services, including bathing or hair care. While personal care services were always an extra cost, some programs included transportation in their daily rate either as a flat fee or on a sliding fee scale. Not all programs could provide “affordable” transportation to the program site. For example, one rural program reported that if they arranged transportation for a client living across their service area using the available county transit system, the cost would be \$130 per round trip making the cost prohibitive for the client/caregiver. Consequently; they did not include transportation in the cost of their program. A summary of the reported costs are provided in Table 5.

Table 5: Summary of program costs to client for full day of service

	Daily rate of ADS	Transportation costs	Bathing costs	Other expenses
Range	\$36-64	\$.0-18	\$10-15	\$8 for hair or nail care
Average	\$49.56	N/A	\$14.00	N/A

Programs reported that the actual unit cost for one day of service was \$55. Appendix E provides a listing of the components one large ADS program uses to calculate a unit cost. Not all programs were able to provide unit cost information either because the accounting was handled by another entity within the larger parent organization and the administrator did not know the amount or because the program had not calculated a unit cost. Generally, the programs that could not report unit costs were smaller and less developed. As stated by one ADS administrator, “I don’t really deal with the budget so I can’t tell you exactly where we can improve.”

Programs reported that on average only 25 percent of their clients were private pay in 2006. Costs for the remaining 75 percent of clients were covered by third party reimbursements. ADS providers, professional trade associations, and other social service and healthcare professionals identified “poor reimbursement rates” as one of the greatest challenges that ADS had to overcome before services could be strengthened.

Third party reimbursement sources for ADS are briefly described below together with general responses from participants regarding each source. It is important to note that overall, ADS administrators and

many other respondents did not have a clear understanding of these funding sources and how to apply for them.

Title XIX Home and Community-Based Waivers

The Title XIX Home and Community-Based Service Waiver consists of several separate programs that reimburse providers for ADS, including the Elderly Waiver, Ill and Handicap Waiver, and the Brain Injury Waiver. Ninety-three percent (n = 26) of the ADS programs indicated that they received Title XIX Home and Community-Based Waivers in 2006. According to Iowa Code, ADS is reimbursed either the Veteran Administration's contract rate or \$21.90 for a half day, \$43.59 for a full day, or \$65.38 for an extended day. The reimbursement for Ill and Handicap waiver is typically higher given the additional funding that comes from the county MH/MR system, however clients must meet specific requirements for this waiver.

Based on the average daily cost of ADS (\$49.56), programs that are reimbursed at the \$43.59 rate lose approximately \$6 per day for each person receiving the Waiver. Based on the unit cost analysis (\$55.00/day), programs lose almost \$12 per day on each participant receiving the Waiver.

Department of Veteran's Affairs

Obtaining information on VA benefits for ADS was difficult due to the lack of information about this benefit within the VA system and knowledgeable sources identifying information regarding benefits as "classified." ADS providers also reported that it was difficult to obtain information from the VA about ADS benefits. This, combined with ADS providers reporting that they "serve few veterans," resulted in only 61% (n = 17) of ADS providers accessing VA benefits in 2006. The ADS programs who did receive VA benefits indicated that reimbursements ranged from \$47/day to \$64/day. The negotiating of VA benefits was typically handled by the accountant or financial manager of the parent organization that supported the ADS; thus, administrators had limited information about how this rate was negotiated or determined. The ADS providers who received the VA benefit were able to negotiate a higher reimbursement than the amount provided by the Medicaid Waiver; thus, this was a cost effective option for ADS programs.

Senior Living Trust Program

The Senior Living Trust Program (Iowa Code 249H) has multiple components. The overall focus of the first component of 249H.5, operated through the Iowa Department of Human Services, is to make changes in the nursing home industry by allowing excess nursing home rooms to be turned into alternate services, including ADS. The second component, funded through the Iowa Department of Elder Affairs (Iowa Administrative Code 321, Chapter 28) and put into operation by the AAA, helps pay for home and community-based services for low and moderate income families.

Forty-three percent (n = 12) of ADS providers received funding through the Senior Living Trust Program in 2006. Two primary mechanisms were used by the AAA to distribute Senior Living Trust funds: Requests for Proposals (RFP) or lump sums to providers to off set costs for low income older adults. In either case, the AAA reported that Senior Living Trust funds were to ensure that all older adults, regardless of income status, had access to needed services.

There was concern among AAA administrators and ADS providers about the current and future availability of Senior Living Trust dollars. Given this uncertainty, participants were unsure as to how viable this funding source would be in the future. The AAA executive directors reported that when deciding how to distribute the Senior Living Trust dollars they had to balance the needs of ADS with other service providers in their area. All AAA executive directors reported that providing funds for ADS was typically discussed and considered; however, some AAA's had decided to support other services in

their region to a greater extent based upon elder's needs and the strength of the other home and community-based services compared to ADS.

Older Americans Act

The Older Americans Act created the Administration on Aging in 1965. The act, signed by Lyndon B. Johnson, authorized grants for community planning and service programs, as well as for research in the field of aging. Later amendments to the Act included grants to AAA for local needs identification, planning, and funding of services. Title III B of the Older American Act discusses services, including ADS.

Thirty-six percent (n = 10) of ADS providers received funding through the Older Americans Act in 2006, specifically the National Family Caregiver Support Program. Administrators were unsure of the specific amount of funding that came from this source, but recognized that it was used to assist caregivers in receiving respite services through ADS.

Child and Adult Care Food Program

The goal of the Child and Adult Care Food Program (CACFP) is to improve the quality of care by providing meal and snack reimbursement to child care center's, day care homes, adult day service centers, at-risk after school programs and emergency shelters. CACFP is administered through grants from the USDA Food and Nutrition Service. In Iowa this funding is administered by the Department of Education.

Forty-three percent (n = 12) of ADS providers in 2006 received funding through the CACFP. The ADS administrators indicated that these funds assisted in offsetting "some of the costs" for lunch and snacks for participants. The ADS who did not receive this funding were either unaware of its availability or did not feel that they were eligible for the program due to their involvement with either a senior center or other parent organization, particularly a long-term care facility. Other ADS programs indicated that they were not using this program due to the extensive paperwork that was involved in receiving the "minor amount of money in return."

Private Long-term Care Insurance

Forty-six percent (n = 13) of ADS received funding for services through their clients' long-term care insurance policies. ADS administrators expressed that the utilization of long-term care insurance was low because many participants had waited too long to explore and/or purchase long-term care insurance and no longer met the health status requirements or were unable to afford the insurance premiums. Participants believed that long-term care insurance will be a greater source of funding for ADS as the baby boomers start accessing this service.

Table 6 summarizes the percent of ADS programs receiving each type of reimbursement in 2006.

Table 6: Percent of ADS programs receiving each type of reimbursement in 2006

Third Party Reimbursement	Percent of ADS who received reimbursement in 2006
Title XIX Home and Community-Based Waiver	93%
AAA contract	70%
Veteran's Administration	61%
Long-term care insurance	46%
Child and Adult Food Program	43%
Senior Living Trust	43%
Older American Act	36%
Other	32%

One-third (n = 9) of the ADS programs received funding from “other” sources in 2006. These sources were typically small grants from the United Way, donations, proceeds from fundraisers, and/or the parent organization off-setting program costs, particularly when the program was operating in a deficit. These funds were not enough to support the program in its entirety, but did allow the program to cover more of their costs or to provide some additional services to consumers.

Some respondents believed that there was a potential for more private pay clients to use ADS, but also held that “older people are likely to keep it in a shoebox rather than spend it on ADS.” Some respondents recognized that the current cohort of elders had been influenced by the Depression and were more likely to want to save their money for emergencies or long-term care rather than spend it on a “luxury” service like as ADS. It was acknowledged by all respondents that “future” generations of elders were less likely to share this philosophy and instead would seek out ADS and other community-based services. As indicated previously, there were also ADS providers who did not believe that they could compete with the marketing of assisted living facilities and would never attract a large group of private pay clients. These providers felt that in the future ADS would continue to be a service that was predominantly used by lower income individuals.

Funding Barriers

A number of funding barriers were identified by the respondents. Universally AAA, ADS providers, and community professionals reported that *reimbursement rates were too low* to meet the actual costs of running a certified ADS program, resulting in programs losing at least \$6 - \$12 per client per day. This was a significant source of frustration for providers who viewed their service as critical to saving state Medicaid dollars that would instead be spent on long-term care. “I think that the per diems [reimbursements] are pathetically low and when you consider the fact that we are keeping people often times from moving into the nursing home or more restrictive care, then we are actually saving the State enormous amounts of money.” From a business model, participants believed that the current reimbursement system is not tenable; leading programs to describe their ADS as a “service to the community” rather than a “business”. This was exemplified by one rural provider who indicated, “We have clients who are unable to financially pay, private pay. We don’t turn anybody away. Consequently,

there will be times, quite often times, where we have to absorb the cost and absorbing the cost certainly doesn't pay the bills.”

Administrators acknowledged that one mechanism to offset portions of these costs is to attract private pay clients who could be charged a slightly higher rate. Programs, however, were reluctant to increase their rates out of fear of severely reducing their private pay client base and placing them in greater financial trouble.

Funding was additionally difficult due to the *changing medical needs* of the ADS clients. Providers reported that participants frequently “came and went” out of ADS because of health reasons, which caused providers to lose money in any given month. In an attempt to procure a stable source of revenue from clients, ADS providers implemented different strategies to ensure payment including: establishing rules for the number of absences that a client could have prior to being charged a daily fee; having private pay clients pay for the entire month of care in advance; charging private pay clients for four weeks per month instead of five if they would pay in advance; and overbooking the number of clients for a given day.

In addition to program costs, respondents identified the *high cost of certification and initial start-up costs* both in terms of the dollar cost and staff time as additional funding barriers for ADS programs. This barrier is discussed in greater detail below.

Many administrators *were unaware of the major funding programs* available for reimbursing ADS. For some, the interview or focus groups they attended as part of this study was the first place they had heard about some funding sources available for their ADS programs. Other administrators had heard of the reimbursement programs, but had minimal knowledge about how to access the funding. Many of these administrators were new to ADS or had budgets managed by an outside (parent) entity. For example, during one interview with an ADS administrator, the evaluator was directed to talk with the program secretary who was “more knowledgeable about the sources of funding and reimbursement for the program.” Some administrators were more aware of funding streams and had sought out additional information about them. They expressed that seeking information was typically a very frustrating process. People from both the VA system and DHS rarely returned their phone calls or when the phone calls were returned the administrators received inconsistent information from different individuals. Thus, consistent answers to their questions and suggestions for growing their business could not be obtained. This resulted not only in frustration, but disempowerment and a sense that their service was viewed as unimportant, as well.

Most ADS administrators indicated that they frequently *operated in a deficit situation*. The administrators recognized their “break even point”, (defined as the number of people who must attend each day for the program to not lose money), but frequently saw reaching a break even point as unobtainable. Statements, such as “We are losing money (everyday)” or “It’s trying to lose the least amount of money” exemplified this sentiment. Most ADS indicated that it took “three to five years” for a break even point to be reached, with several reporting that they have never reached a break even point even after five years. Administrators reported that parent organizations frequently had to offset the costs of the ADS deficit, thus placing some programs in jeopardy of being closed if their financial status did not improve.

Table 7 summarizes the funding barriers identified and the respondent groups identifying each barrier.

Table 7: Funding barriers and respondent groups identifying each barrier

Funding Barriers	Respondents				
	DEA	Professional Trade Association	AAA	ADS	Community Professionals
Reimbursement for ADS too low			✓	✓	✓
Difficulty “breaking even”	✓		✓	✓	✓
Lack of knowledge of ADS funding streams			✓	✓	✓
Difficulty attracting private pay clients				✓	✓
High cost of certification		✓	✓	✓	✓
Lack of adequate ADS “start up funds”		✓	✓	✓	✓

Adequacy of Third Party Reimbursements

Based on the analysis of the third party reimbursement system, the ability of the ADS industry to be financially viable without additional or stronger funding and reimbursement streams is questionable. Even the larger and more established ADS providers indicated that they regularly operated in deficit situations due to poor reimbursements; thus, this occurrence was not isolated to smaller, rural, and less established programs. In the current system, fundraising, grant writing, and accessing dollars from other community entities, such as the United Way has been the only way for providers to offset costs. However, to secure this revenue has required considerable time from the administrators, which, as indicated previously, was not always available. For many ADS programs, parent organizations offset costs through funding from other programs or funding sources, thereby putting their programs in jeopardy with the parent organization because they were not viewed as self-sufficient. Due to funding issues, three of the ADS programs indicated that they were at risk of being closed in the next year; one was unsure if the hospital system was going to continue to support their service as the hospital looked to expand. Less established ADS providers were in greatest jeopardy for being closed due to funding, particularly those programs that had fewer staff and required the administrator to provide more direct care, decreasing time available for fundraising and grant writing. The ability for ADS providers to obtain information on funding to help strengthen their program was difficult and inconsistent information was provided. Administrators indicated that they did not have the time to “track down people” to obtain accurate information on funding and reimbursement. Clearly these situations need to be rectified before ADS can be strengthened in Iowa.

Review of Iowa Code 231D and Iowa Administrative Code 321, Chapter 24

Participants were frequently not familiar with the details of the Iowa Code and Administrative Rules relating to ADS, although almost all participants knew that they existed. It was agreed by all participants that the Code and Rules provided for the quality of service that ensured the safety of participants and a consistent framework for ADS programs across the state. However, a number of concerns with the Code and Rules were identified by respondents.

Respondents from both rural and urban communities felt strongly that the Code and Rules limited the ability of ADS to be successful in rural areas of the state. As stated by one respondent, “There will never be a [name of urban ADS program] in Sioux Center, Iowa.” The Code and Rules define a “business” and the rural communities, in particular, viewed their ADS or an ADS provider as a “service” to the

community residents. Given the small population base and the other barriers identified above, it was not feasible for many communities to support an ADS program because the costs to establish and conduct the “business” were too prohibitive given the small number of potential clients, transportation, and geographic distance issues. Typically, in rural areas, ADS programs were most likely to be run within a nursing home or hospital. Running a “business within a business,” while possible, was not well understood by potential or current providers. This business model was being used by only one ADS provider.

Participants identified differences between “urban” and “rural” models of ADS. Urban ADS were more likely to be housed in a free standing building (though not necessarily free standing financially). It was felt that the licensing criteria seemed to fit the needs of the DIA to ensure that the program was run with the best interest of the client in mind, but was not sensitive to rural communities who were unable to have a free standing building or program and would never attract the volume of ADS clients that would be seen in an urban area of the state. Rural communities that did not have an ADS believed that an ADS would fit best within a nursing home or hospital setting that was already fully accredited, licensed, and regularly inspected by another accrediting body. Thus, needing to meet additional ADS criteria and pay the additional licensing fee was seen as burdensome and at times discouraged potential ADS providers from exploring the feasibility of starting a program.

As noted in the description of programs above, administrator training and education is not required in the ADS Legislative Code. Requiring a certain level of professional training would be one way to ensure that administrators and staff are adequately prepared to address the needs of a program and its clients. Participants recognized that ADS programs would be stronger if administrators were required to have a minimum education/training level because of the complexity of running an ADS program. In survey responses, administrators reportedly had completed between 12 and 18 years of education. Some had completed additional business management courses to assist them with managing the program. Similarly, there was a recognition that on-going training requirements for staff should extend beyond the minimum six hour dementia-specific education that is already required. The many needs of ADS clients is particularly challenging without more extensive on-going training. Mandatory training, particularly for administrators, is required for other professional groups and settings (e.g. nursing homes and assisted living) and therefore seems like an appropriate and fitting adaptation for ADS.

For both urban and rural ADS providers, the actual fee for certification was seen to be overwhelming. This was particularly true for the smaller or newer ADS providers who were more constrained by a limited client base, were operating in a deficit, and were more likely to lack the funding to pay for the certification fee. According to one ADS administrator, “The certification is like \$750 to get started and \$1000 every two years...That’s a huge expense, if you do any kind of like draw blood for blood sugars, you have to have a certificate for that, which is another \$150. It’s ridiculous. They need to say, if you have this many clients, this is your fee.” Many participants believed that a tiered fee system based upon program capacity would be a more equitable fee system.

Another concern expressed about the present ADS Code and Rules was that they are duplicative of the Assistive Living code and rules – some respondents felt they were identical. Because the two programs serve different populations, one requiring residential services (Assisted Living) and the other only needing home support (ADS), participants believed that the present ADS requirements were too stringent for the level of service needed by consumers. Statements, such as “We don’t provide 24 hour care” and “Twenty-four hour medication management and documentation is different than what we do” exemplified these views. Program administrators believed that if the Code and Rules were modified to reflect the unique ADS programs, it would be easier to start and build programs across the state.

Technical Assistance Needs and the Provision of Technical Support

Technical assistance needs were identified in two primary areas: developing a business model and growing a business. The survey results from ADS providers identified that the primary areas of technical assistance needed for growing a business were *administrator development and training, understanding reimbursement, funding and budgets, understanding regulations, and developing a business model*. Closely related are technical assistance needs to expand or strengthen a program once it is established. Examples of these needs include: *marketing, identifying future clients, strengthening community relationships, measuring staff competencies, staff training, and obtaining best practices for ADS*. Technical assistance needs in both of these areas were identified by ADS administrators and in focus groups and interviews.

Participants recognized that these technical assistance needs are reflexive. Program administrators reported they needed to better understand the regulations for ADS and how to develop their program to meet them. This included preparing for the Department of Inspection and Appeals survey for certification or recertification. Administrators who did not have long-term care experience did not have a clear understanding of the survey process and how to prepare for their ADS for review. To attract more clients, administrators needed assistance in developing and implementing a marketing plan. Technical assistance to identify funding sources and completing required paperwork was identified as a fundamental and on-going need as requirements and procedures for these funding sources change frequently. As noted above, some program administrators were unaware of the funding and reimbursement options available to them or were unable to obtain the necessary information to receive the reimbursement. Collectively, after receiving technical assistance in these areas, the administrators would be better able to develop a business model. However, having additional assistance to develop that model was also identified

Once a business model is in place and a program is functional, participants believed that it was important to train staff for best practice, identify supervisory and leadership roles in the program, build the client base through community education, and strengthen community relationships. Participants identified each of these areas as critical to maintaining a program. All program administrators identified multiple needs in these areas.

In addition to the individual ADS providers, the IASDA would benefit from technical assistance support. As stated earlier, IASDA does not have a website which limits its ability to economically distribute timely information among its members and to recruit new members. Not all ADS providers in the state are members of the Association and several were unaware that an ADS association existed in Iowa. Technical assistance to develop and maintain a website would benefit the entire ADS network. Presently, individual ADS providers receive different amounts of information from the Association about funding and state regulations. This was even true among administrators who were members of the IASDA board of directors, with several board members having no knowledge of current Association initiatives and pilot programs.

IASDA would also benefit from technical assistance to develop a network of communication among ADS programs and between IASDA and the state regulating bodies and the national associations. Without an established communication network, program administrators are not able to easily learn from each other and share important information, which would contribute to the industry's growth and expansion.

A number of respondents also suggested that members of the IASDA who had demonstrated a strong interest in ADS would be likely persons to assume leadership or advocacy positions within the ADS network. To do this effectively, however, advocacy/leadership mentoring and/or training would be required. It was also recognized that at the present time persons involved with IASDA were the same administrators who were already overly committed to running their own ADS program.

Table 8 provides a summary of the technical assistance needs identified by the participants.

Table 8: Technical assistance needs identified by participants

Technical assistance need	Respondents					
	DEA	Professional Trade Association	AAA	ADS	Community Professionals	Caregivers
Development of business model	✓			✓	✓	
Understanding funding and reimbursement				✓		
Understanding ADS regulation		✓	✓	✓		
Administrator and staff training				✓	✓	
Mentoring for ADS providers			✓	✓		
Development of marketing and public education strategies			✓	✓		✓
Strengthening a business		✓	✓	✓		
Identifying potential clients				✓		
Strengthening community relationships				✓		
Measuring staff competencies				✓		
Job distribution within ADS service			✓	✓		
Obtaining best practices				✓		
IASDA infrastructure				✓		
Vertical and horizontal communication structures			✓	✓		
Leadership development among ADS providers		✓	✓	✓		

One of the most significant questions that ADS providers and AAA executive directors asked was related to who would provide technical support to the ADS. While some questioned if this could be the role of the IASDA, it was felt that at this time this organization did not have the necessary infrastructure to provide any form of technical assistance, particularly because they also needed technical assistance to be able to grow into a stronger association. With the AAA not identifying ADS as a service priority, most executive directors were uncomfortable directing their staffs' time and monetary resources to ADS at the

expense of other services. The professional trade associations also did not see their role as providing technical assistance to ADS. Several of the associations assumed technical assistance was already being provided, such as one association that stated “I assume they are receiving enough technical support”, while several others questioned the need for it given that communities do not have enough clients to “even support an adult day.” All professionals were candid they did not believe it was feasible for the Department of Elder Affairs to assume the lead on providing ADS with technical assistance and did not feel the AAA received enough funding to provide the types of support that were needed.

One potential resource to provide technical support to the Iowa ADS industry is the Iowa Association of Homes and Services for the Aging. At the national level, the National Adult Day Association is in partnership with the American Association of Homes and Services for the Aging (AAHSA). AAHSA is responsible for the policy agenda and lobbying for the National Adult Day Association. AASHA initiated a plan for pilot partnerships to be formed between state adult day associations and state associations of Homes and Services for the Aging. IADSA is participating in this partnership and will be receiving additional support from the Iowa Association of Homes and Services for the Aging⁴. This may be a first critical step in strengthening the IADSA.

Opportunities for Growth

Despite the many barriers to providing adult day services, ADS providers and other participants were enthusiastic about, and highly supportive of, the service. Despite being candid that the barriers at times felt insurmountable, they also saw many opportunities for growth within the ADS industry in Iowa during the next five years. The opportunities for growth expressed by all adult day providers included:

- Increased awareness of adult day services in Iowa and nationally
- Forming partnership with assisted living programs
- Expanding older adult client base as more people reach 65
- Growth of the brain injury population due to the current war in Iraq
- Development of innovative programs that include new treatments, including massage and aromatherapy

The urban ADS also saw additional opportunities for growth more pertinent to the larger scale programs in these locations. They included:

- New capital campaigns and new building construction plans scheduled for next five years
- The creation of programming for high and low functioning clients
- Partnerships with local universities and colleges.

ADS providers and community professionals saw this evaluation as another opportunity for growth. Many of the community professionals who participated in the focus groups had never met and were unfamiliar with ADS. Their purpose in attending the group was to “learn more” and to “meet other providers.” Dialogue was started during the focus groups about the changing demographics within communities, the realization of the need for ADS in their communities, and the potential for collaboration that will hopefully continue in the future.

Summary and Recommendations

This evaluation produced findings that have been found in other research and evaluations of ADS in the United States. In 2002, the Partners in Caregiving initiative determined that ADS in Iowa was operating at a utilization rate of 58%. The current evaluation found that ADS had a current utilization rate of 70% in 2006, which demonstrates growth in the program over the last five years. The unit cost daily fee of ADS in Iowa has increased since the 2002 evaluation from \$45 to \$55. The average daily rate has also increased from \$42 to \$49.56. Thus, while the unit cost has increased approximately \$10 in the last five years, the private pay fee has only increased approximately \$7. The percentage of Medicaid eligible ADS participants has greatly increased over the last five years. The Partners in Caregiving evaluation reported that 46% of participants were Medicaid eligible, while the current evaluation determined that 75% of current ADS participants are being funded through third party reimbursement, most commonly the Medicaid Waiver program. This, combined with low reimbursement rates, has resulted in programs operating in deficit situations.

Other evaluations of ADS support the findings from this evaluation of the Iowa ADS system. O'Keefe and Siebenaler,⁵ in an evaluation of the ADS program in five states that was funded through the U.S. Department of Health and Human Services, determined that none of the ADS programs that were evaluated could meet their costs through only private pay and third party reimbursements; all of the programs relied on other sources of funding, such as donations, fundraising, or subsidies from parent organizations. Like the present evaluation, O'Keefe and Siebenaler concluded that "reimbursement rates were not sufficient to meet costs" of ADS programs (p. ix). O'Keefe and Siebenaler also found that structural barriers prevented the growth and expansion of ADS. Issues such as transportation, lack of professional and caregiver awareness of ADS, and the need for public education on the benefits of ADS were needed to be strengthened before programs could grow.

At the current time, ADS programs in Iowa are surviving because of highly dedicated administrators and staff who are willing to spend long hours and their personal time trying to grow their business and serve their communities. Programs are also surviving because some parent organizations are willing to provide financial resources to keep the doors of this service open despite financial performance. However, should either of these factors change, it is unclear how viable this home and community-based service will be without outside intervention. From the data that were collected, recommendations emerged that will help create a stronger ADS infrastructure and potentially ensure the longevity of this program in Iowa. Some of the recommendations require policy changes, while others require the development and support of the ADS industry itself. All of the recommendations are related to each other, but identify pertinent aspects of the identified issue.

- 1. Development of state-wide task force:** Given the number and variety of problems and issues identified by the participants in this statewide evaluation, and the very limited time that the present program administrators had to address these issues, the establishment of a statewide task force to systematically address the issues identified in this report would ensure that ADS would become a more stronger and more viable service for older adults in Iowa. The task force should be comprised of Iowa and national experts on ADS, business developers, leadership trainers, legislators, and program evaluators, as well as program administrators, consumers and their caregivers.
- 2. Mandatory training for ADS administrators:** Many ADS administrators lack specific administrative training, which is essential to building a successful program. Additionally, many had limited knowledge about the intricacies of reimbursement systems and regulations that are needed to run an ADS. Administrative training, which should include accounting/budgeting, funding, regulations, supervision, and marketing/public education information, would provide

them with the necessary knowledge to develop a business model and successfully navigate the certification process. Establishing a mandatory training program for ADS administrators would also assist in the distribution of accurate information on funding, reimbursement, and regulations that is currently lacking with in the ADS system.

3. **Evaluate the affordability and accessibility of transportation in Iowa:** Overwhelmingly, transportation was identified as the most significant barrier to the growth of ADS. ADS requires individuals to leave their homes to access the service. For many caregivers, it is unrealistic for them to serve as the primary source of transit for the care recipient to and from ADS due their impaired health status, inability to drive, employment status, or overall feelings of stress and burden. The ADS programs that did not provide transportation services consistently identified this as one of the factors that was limiting their growth and expansion. However, due to funding, they were unable to afford to offer this service. Determining a way for transportation to be built into the ADS system is one clear way to strengthening this service. The lack of transportation is currently a regional, county, and city issue. For those people in the most rural areas of Iowa, the lack of transportation to and from services excludes them from participating in many of the health related services that could improve their quality of life as they age.
4. **Increase funding through the Title XIX Home and Community-Based Waivers and other sources:** Daily reimbursement for ADS is too low and is one of the contributors for providers losing money. On average, providers receive \$12.00 less than their unit cost for ADS. Raising the daily reimbursement rate for ADS may also trigger need to raise total cap from \$1084 per month. While it is recognized that Medicaid dollars are limited and priorities must be chosen, approximately three out of four ADS consumers rely on third party reimbursement to pay for their service. Thus, sufficient funding from the Medicaid Waiver program to support ADS programs is essential.

Additionally, other sources of funding from the state must be explored to support ADS.

With it taking ADS providers up to five years to reach a break even point, start-up funds for ADS programs and reconsidering the certification fee are needed. ADS programs have the potential to save the state million of Medicaid dollars that would be directed to long-term care services for dependent individuals. Unless ADS programs have sufficient reimbursement and funding, they will continue to financially struggle.

5. **Develop an infrastructure to support the network of ADS programs.** At the current time, the ADS service network lacks the necessary infrastructure to be successful. The exchange of information between ADS providers, as well as between state agencies and ADS providers is not effective with some providers having certain pieces of information and others having minimal information. The needed infrastructure would include:
 - a. Establishing and supporting a system of communication *between* individual ADS providers and *between* ADS providers and state entities (DIA, DEA, IADSA), which would include regular mailings and websites detailing changes in reimbursement and funding, regulations, and providing a forum for people to receive answers to their questions about running an ADS.
 - b. Mandatory training for ADS administrators as described in recommendation #1.
 - c. Strengthen IADSA to facilitate communication and efficiency in providing critical information to program administrators and to offer support to administrators. At least initially, this may require providing technical assistance to and funding for a staff person to develop an association website and list serve between IADSA members.
 - d. Mentoring system for either new ADS programs or programs that are looking to grow or expand their business.

6. **Consider the differences between rural and urban ADS programs.** There is a need for ADS programs in rural areas. However, the sentiment of the current providers is that ADS in rural areas will never be like the programs that are found in areas with populations over 100,000. Additionally, it is questionable if the most rural areas of the state could support an ADS. The Partners in Caregiving report indicates that the populations of communities must be at least 20,000 to support an ADS, with at least 1% of the population (200 people) who could be potential consumers of the ADS service. With over 50% of the counties in Iowa having a *county population* of less than 25,000, an ADS program such as one that is found in a more urban area of the state is not feasible. The geographic distribution of ADS programs demonstrates that the most rural areas of Iowa are underserved and from the data that were collected caregivers are struggling with how to obtain respite and therapeutic home and community-based services for their care recipients.

ADS programs are needed in rural communities, but considerations need to be made about how ADS programs in these areas of the state can be successful. Options, such as a tiered system of certification for different geographic areas, devoting greater technical support and mentoring to rural communities during the implementation of and the first years of the ADS, and creating greater flexibility for the use of existing services, such as nursing homes, for ADS programs, should be examined to determine feasibility. Additionally, support for transportation services to assist clients in accessing ADS services should be considered. Health and social service professionals in rural areas want to provide an ADS and feel that it would greatly benefit their community. But, until ADS is structured in a way that is conducive to the constraints of many rural areas, ADS will most likely not be able to be provided. Examining how other rural states provide ADS services may be an initial step in this process.

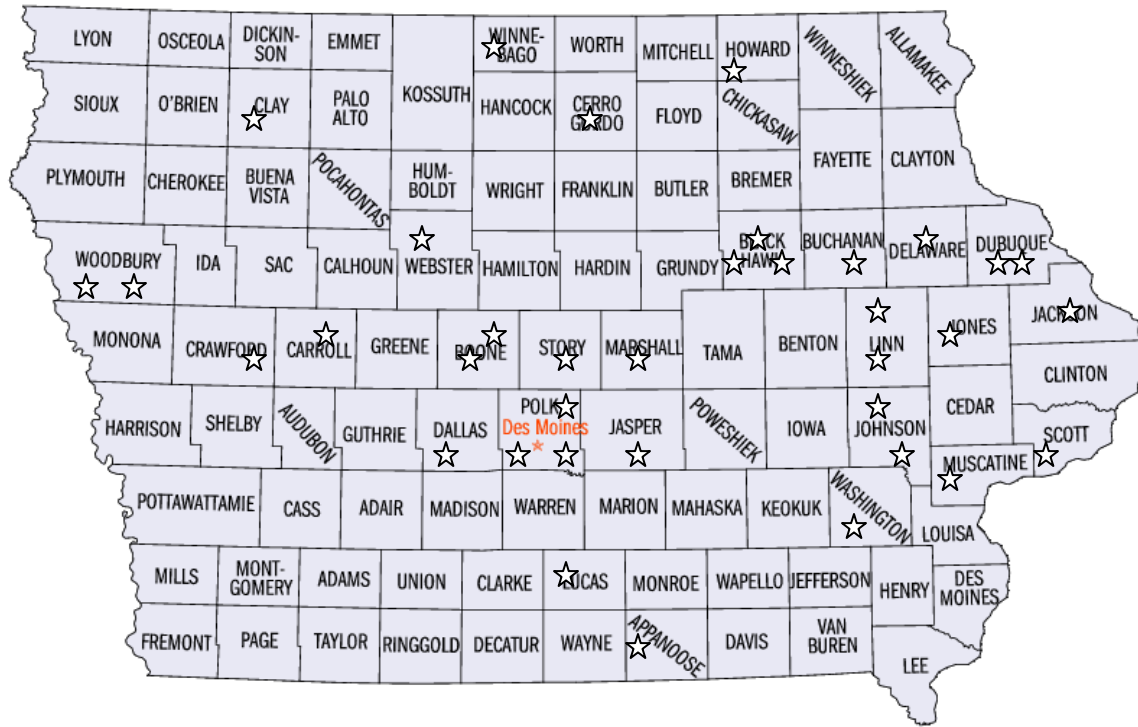
7. **Implement a statewide public education campaign about ADS.** The focus groups revealed a lack of knowledge that health and social service providers had about ADS. This was particularly concerning because the professionals who attended the focus groups interfaced with clients on a daily basis who could be referred to ADS programs. This education would not only assist in educating people about ADS, but also laying the foundation for professionals to consider implementing an ADS in the underserved areas of the state.
8. **Education for providers about the difference between in-facility respite care and ADS.** As indicated previously, confusion still exists over the terms “respite” and “adult day services”. Community and long-term care professionals used the words interchangeably. ADS providers also were unclear about what constituted a respite service versus what they provided through their program. It was found that long-term care facilities continued to refer to their respite service as ADS even though they were not certified through the DIA. This issue was particularly confusing for caregivers who thought they were sending the care recipient to one service only to learn that it could not be reimbursed through the waiver due to regulatory issues.
9. **Identify an entity that will help strengthen ADS in Iowa.** ADS is needed in Iowa; however, the service must be strengthened. Iowa has several strong ADS programs; however their administrators do not have the time to mentor smaller ADS programs. For the ADS system as a whole to be strengthened, some entity needs to step forward to provide the leadership and mentoring that is needed and desired by the current ADS programs. Unless a key person or entity is identified, such as the Iowa Association of Homes and Services for the Aging, it is questionable if many of the current programs in the state will exist in the next 5 years. The pilot program that is being developed between IADSA and the Iowa Association of Homes and Services for the Aging is only one step in this process and cannot be viewed as the only solution to this issue. The

establishment of other initiatives, including an ADS mentoring system, hotline for answering regulatory and reimbursement issues, and an on-going training program, must also occur.

- 10. Conduct a needs assessment of Home and Community-Based Services in rural areas.** While the focus groups were specific to ADS, professionals discussed other service needs that individuals faced in their communities. A common theme that developed in these discussions was that older adult and MR/DD populations do not want to mix and participate in services together. A needs assessment should look not only at needed services, but also an analysis of funding streams to support future programs. Additionally, a needs assessment should examine locations throughout the state that would be strategic locations for services so that individuals from a greater geographic area could access support. While this type of needs assessment would be time intensive, it would be extremely valuable as the state looks at the provision of services for older adults over the next 10 to 15 years.

Appendix A

Location of Iowa ADS Programs



Appendix B

Survey of ADS Providers

Adult Day Care Provider Survey

Please provide the following information about your adult day care program. We may contact you for further information.

YES, I have read and understand the attached information letter.

1. Name of the program: _____

2. Name of Executive Director: _____

3. Credentials of Executive Director: _____

4. Role(s) of Executive Director (please circle):

Administrator Activity Planner/Facilitator Family Support Provider

Community Education Other: _____

5. Number of staff: _____ 6. Full-time% _____ 7. Part-time% _____

8. Average staff to client ratio: _____

9. Staff credentials: _____

10. Please describe your in-house training programs for staff (type, duration, topic):

11. Hours of operation: _____ Days per week: Su M T W TH F Sa

12. Primary focus of services:

_____ Social _____ Medical _____ Social and Medical (combination)

13. Maximum daily capacity: _____

14. Average daily census 2004 : _____ 2005: _____ 2006: _____

15. How many individuals total (unduplicated count) were served in:

2004: _____ 2005: _____ 2006: _____

16. Are you a member of any of the following, please circle:

Iowa Adult Day Care Association

National Adult Day Services Association

Gerontological Society of America

American Society on Aging

Other (please indicate): _____

17. Are you eligible to receive reimbursement from any of the following, please check all that apply:

Child and Adult Food Program

Senior Living Program

Older Americans Act

Contract with Area Agencies on Aging

Private Long-Term Care Insurance

Department of Veteran's Affairs

Title XIX Home and Community Based Service Waivers

Other (please indicate): _____

18. Is your facility: (check one)

Non-profit

For-profit

Government based

Other _____

19. Is your facility: (check one)

Free-standing facility

Part of residential facility

Part of a senior living community Other (please indicate) : _____

Please indicate where you are with respect to the state licensure process:

20. We are considering becoming certified with the Department of Inspections and Appeals of Iowa as an adult day-care program: (circle one) Yes No

21. We are not considering becoming certified with the Department of Inspections and Appeals of Iowa as an adult day-care program: (circle one) Yes No

22. We are presently certified with the Department of Inspections and Appeals of Iowa as an adult day-care program: (circle one) Yes No

If certified, when did this occur? (m/d/y) _____

23. We are accredited by Commission on Accreditation of Rehabilitation Facilities (CARF)?

Yes

No

Please answer the following questions specific to your client population in 2006.

24. Gender of participants (please provide percentages) in 2006: _____Male _____Female

25. Range in age of participants in 2006: _____

26. Reasons for attending in 2006: (check all that apply *and* approximate percentage for each category)

_____ Dementia _____%

_____ Physical health problems _____%

_____ Developmental disabilities _____%

_____ Mental illness _____%

_____ Other: _____%

27. In 2006 clients were referred by:

28. What % of the population you served were private pay in 2006? _____

29. What % of the population you served were 3rd party reimbursed in 2006? _____

30. In 2006, we were reimbursed by (check all that apply):

Child and Adult Food Program

Senior Living Program

Older Americans Act

Contract with Area Agencies on Aging

Private Long-Term Care Insurance

Department of Veteran's Affairs

Title XIX Home and Community Based Service Waivers

Other (please indicate): _____

31. What was the geographic service area of you Adult Day Care (cities, counties) in 2006?

32. What was the farthest distance a participant had to drive in order to receive your services in 2006?

Please answer the following questions, providing as much detail as possible.

33. What would you identify as the barriers to individuals accessing adult day care services in your area?

34. What would you identify as the greatest strengths of your program?

35. What opportunities for growth are you exploring for the next year? Next 5 years?

36. Have you been impacted by the changes in the Iowa Code in the last decade? If so, please explain how?

37. If you provided Adult Day-Care services at one time, but no longer do at present, please explain why.

38. Please identify which of the following needs you have: (check all that apply)

_____Need for assistance in developing a business plan

- _____ Need for assistance in identifying future clients
- _____ Need for assistance in developing a marketing program
- _____ Need for assistance with capital construction costs
- _____ Need for assistance in building community relationships and partners for support
- _____ Need for assistance in meeting the best practices outlined by the ADC industry
- _____ Need for assistance in training staff to better work with clients
- _____ Need for assistance in measuring staff competency

Please enclose this form in the self addressed stamped envelope provided in your packet. If you have any questions about the project, please contact Dr. Sara Sanders at 319-335-2079 or sara-sanders@uiowa.edu or Dr. Jeanne Saunders at 319-336-1276 or jeanne-saunders@uiowa.edu. We will be contacting you in the next few weeks to provide you with additional information about the interview phase of this project and the consent process.

Thank you for your time and consideration.

Appendix C

Recruitment Fliers for Professional and Caregivers Focus Groups

*You are invited to participate in a
Focus Group on Home and Community-
Based Services for the Elderly!*

Little is known about Adult Day Services in Iowa. We **need your assistance** as a Gerontology Professional to identify the strengths, weaknesses and opportunities for growth in Adult Day Services.

Drs. Sara Sanders and Jeanne Saunders, both assistant professors in the School of Social Work at the **University of Iowa** are conducting a focus group to hear **your** views about adult day services.



DATE, 2007 from

Location:

If you are **interested in participating** in or learning more about this research study, please contact Sara Sanders, Ph.D, MSW at 319-335-2079 or sara-sanders@uiowa.edu and *reserve your seat!*

*You are invited to participate in a
Focus Group on Home and Community-
Based Services for the Elderly!*

We need your assistance as a **Caregiver** to identify the strengths, weaknesses and opportunities for growth in Home and Community-Based Services.

Drs. Sara Sanders and Jeanne Saunders, both assistant professors in the School of Social Work at the **University of Iowa** are conducting a focus group to hear your views about elderly services.



DATE, 2007 from

Location:

If you are **interested in participating** in or learning more about this research study, please contact Sara Sanders, Ph.D, MSW at 319-335-2079 or sara-sanders@uiowa.edu and *reserve your seat!*

Appendix D

Semi-structured Interview Guide for Focus Groups

Semi-structured Interview Guide for Focus Groups

Caregivers:

1. Please tell me about how you became a caregiver?
2. What are the current needs of the care recipient?
3. What types of services have you used with the care recipient in the past and currently? What types of services do you anticipate needing in the future?
4. How have you identified possible services for the care recipient? (including word of mouth, case manager, etc)?
5. What types of respite services have you used for the care recipient?
6. What do you know about Adult Day Services?
7. What benefits do you feel service like ADS would have for the care recipient?
8. How would Adult Day Services be helpful to you? (Language in our legislation is geared to helping the “caregiver” as recipient).
9. What challenges or obstacles do you feel you would face by using ADS vs. other community based programs?
10. What challenges or obstacles do you feel the care recipient might face by using Adult Day Services or other community based programs?
11. What would be the ideal ADS program for your care recipient (consider staffing, services, costs, availability)?
12. Why did you chose to use or not use Adult Day Services?
13. What do you see as the strengths of ADS, from your experience?
14. What do you see as some of the weaknesses or gaps in services in ADS, from your experience?

Professionals:

1. Introductions
2. The number of people who are over age 65 is rapidly growing in Iowa. How is this trend impacting your community and the work of gerontological service providers?
3. Can you please provide me with an overview of the types of services that are available for older adults in this community? Please consider those for healthy older adults as well as those for older adults who are experiencing some health crisis or an increased level of dependency.
4. What are the main community-based services that are used in your community? Do you believe that these services are sufficient in meeting the needs of people?

5. What would you identify as the primary service needs of the older adults in your community? How do you think these needs will change over the next 10 years?
6. In your work with older adults, what are the primary services that you feel older adults are requesting OR need?
7. There seems to be a strong push (from who – legislators, communities, field of aging?) towards community-based services for older adults instead of looking to institutionalized care. Would you say that this pattern is also occurring in your community? If so, what does this look like – or how is this impacting your services?
8. We want to shift gears and start focusing specifically on adult day services. Can you please provide me with some historical information about adult day services in your community? (historical data, changes, perceptions, funding, etc). What has been the historical community and professional responses to ADS?
9. What role do you see your agency playing with adult day services?
10. Legislation was passed in Iowa that created more regulations for ADS in Iowa. In what ways do you feel these legislative changes impacted ADS in your region? Do you believe that (all or part of)the legislation was needed? Do you think there are parts of ADS legislation that were helpful and portions that were not?
11. With the passing of the adult day services legislation, a great distinction between respite care and ADS seems to have developed. Can you please share with me how you distinguish these two services? Does respite look the same from facility to facility? In your community, are you finding more respite care being provided informally by long-term care facilities or other entities? Have facilities that once provided ADS now provide respite due to legislative or demographic changes? What is your opinion about long-term care facilities providing respite care to individuals?
12. How sufficient do you feel the Medicaid HCBS Waiver program is for meeting the service needs of older adults?
13. You interface with many older adults, their caregivers, and their families. How frequently do you have requests for ADS? How frequently do you suggest ADS for families?
14. How do you feel consumers and caregivers feel about ADS? How do you perceive the professional gerontological community feels about ADS?
15. What do you think are the benefits of ADS for consumers, communities, and professionals?
16. What do you think are the challenges for developing and sustaining an ADS?
17. Do you think ADS could be strengthened? Should this be where our professional community is focusing its energies?
18. Technical assistance needs of adult day care

Appendix E
Unit Cost Analysis

Elements used for Unit Cost Analysis

Administrative over head
Building Costs
Dues to professional organizations
Insurance
Staff development and training
Staff salary/benefits
Time
Utilities, repairs and maintenance
Vehicle transportation, mileage and maintenance

Averages \$55.00 / person / day

For additional information about the unit cost of ADS in Iowa, please see the Partners in Caregiving report and the “Adult Day Care Feasibility Study” which was completed in 2005 by Bryan Ziegler for the Burlington, Iowa area.

Endnotes

¹ Partners in Caring (2002). *National Study of Adult Day Services*. Wake Forest University, School of Medicine.

² Terms “administrator” and “executive director” were used interchangeably by participants in this evaluation. The term “administrator” will be used to refer to the person in the main managerial role at the ADS.

³ Padgett, D. (1998). *Qualitative methods in social work research*. Thousand Oaks, CA: Sage Publications.

⁴ Personal communication with Katie Smith-Sloan from AAHSA, June 8, 2007.

⁵ O’Keefe, J. & Sienbaler, K. (2006). *Adult day services: A key community service for older adults*. Office of Disability, Aging, and Long-term Care Policy. U.S. Department of Health and Human Services. Washington, DC.