

### NORTH CAROLINA GENERAL ASSEMBLY

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October 1, 2014

Senator Fletcher L. Hartsell, Jr., Co-Chair, Joint Legislative Program Evaluation Oversight Committee Representative Julia Howard, Co-Chair, Joint Legislative Program Evaluation Oversight Committee

North Carolina General Assembly Legislative Building 16 West Jones Street Raleigh, NC 27601

Honorable Co-Chairs:

Session Law 2011-104 authorized the Department of Health and Human Services to pilot an overnight respite program in facilities that provide adult day care and directed the Program Evaluation Division to evaluate the success of the pilot. The legislatively mandated due date for this report is October 1, 2014.

I am pleased to report that the Department of Health and Human Services cooperated with us fully and was at all times courteous to our evaluators during the evaluation.

Sincerely,

John W. Turcotte

Director



## **PROGRAM EVALUATION DIVISION**

### NORTH CAROLINA GENERAL ASSEMBLY

October 2014 Report No. 2014-11

# Overnight Respite Pilot at Adult Day Care Facilities Perceived as Favorable, but Lacked Objective Measures of Success

## **Summary**

As directed by Session Law 2011-104, this evaluation examines the success of a pilot program authorized to provide overnight respite at adult day care facilities in North Carolina. Adult day care facilities already provide daytime respite to caregivers, but in 2011 the General Assembly authorized the Department of Health and Human Services (DHHS) to pilot overnight respite at these facilities. Overnight respite provides temporary relief to caregivers of individuals who are elderly or have a physical disability or mental impairment. Session Law 2011-104 authorized a new setting for the provision of this service through a pilot program at four adult day care facilities across North Carolina: CarePartners (Asheville), Elderhaus (Wilmington), Life Enrichment Center (Shelby), and Southeastern Adult Day Services (Raleigh).

Participants, caregivers, pilot facilities, and DHHS perceive the pilot as successful, but only one pilot facility consistently provided overnight respite. Three pilot facilities saw overnight clients during the pilot, but only CarePartners in Asheville consistently provided the service.

The legislative mandate for the overnight respite pilot and DHHS's implementation of the pilot only met two of the ten recommended components of a well-designed pilot program. Examples of components partially implemented or not implemented at all include a conceptual framework, performance criteria for judging the success of the pilot, and a study design allowing for meaningful evaluation.

The legislative prohibition against using state or Medicaid funding for overnight respite in adult day care facilities hindered the effectiveness of the pilot. Adult day care facilities are eligible for state and Medicaid funding for daytime services, but not for overnight services. Caregivers, pilot facilities, and DHHS cited restrictions on state and Medicaid funding as a primary obstacle to the success of the pilot.

No organization affiliated with respite care maintains data on the need for the service. Interviews with respite stakeholders revealed a lack of data demonstrating the need for the service. The Program Evaluation Division attempted to quantify demand through surveys of pilot participants and caregivers, but these findings may not be generalizable.

#### To address these findings, the General Assembly should

- allow the pilot program authorizing overnight respite at adult day care facilities to expire on June 1, 2015, thereby ceasing overnight respite services in adult day care facilities; and
- require state agencies and institutions initiating pilot projects to adhere to standards established by UNC's School of Government.

## Purpose and Scope

Session Law 2011-104 authorized the Department of Health and Human Services to pilot an overnight respite program in facilities that provide adult day care and directed the Program Evaluation Division to evaluate the success of the pilot.<sup>1</sup>

Three research questions guided this evaluation:

- 1. What is the current status of the overnight respite pilot program?
- 2. How successful was the overnight respite pilot program as measured by participants, caregivers, facilities, and the Department of Health and Human Services?
- 3. What is the feasibility of continuing to provide overnight respite in adult day care facilities?

The Program Evaluation Division collected data from several sources, including

- interviews with and data queries of the Department of Health and Human Services' Division of Aging and Adult Services, Division of Health Service Regulation, Division of Medical Assistance, and Division of State-Operated Health Care Facilities;
- interviews of and site visits to the four facilities selected for the pilot program;
- surveys of caregivers who did and did not use overnight respite at the pilot facilities;
- surveys of all adult day care facilities statewide; and
- interviews of stakeholder associations and two Area Agencies on Aging covering the counties of two of the pilot sites.

## **Background**

As the population ages, the importance of supporting caregivers in their efforts to keep family members at home increases. Between 1984 and 2004, the use of skilled nursing and other residential facilities declined by 37% among the older population—saving Medicaid \$24 billion nationwide.<sup>2</sup> This decline occurred as the number of older people living in community settings who have two or more needs for assistance with activities of daily living rose by two-thirds. Family caregivers—including family members, partners, and close friends—are a key factor in keeping older individuals and individuals with disabilities in their communities as opposed to institutions.

In the United States, as baby boomers transition from being caregivers to those needing care, the population available to be caregivers will increase only 1% from 2010 to 2030, compared to a 79% increase in the population requiring care.<sup>3</sup> North Carolina's ratio of caregivers per care recipient is expected to decline from 8.0 in 2010 to 3.9 in 2030. This

<sup>&</sup>lt;sup>1</sup> N.C. Sess. Law 2011-104.

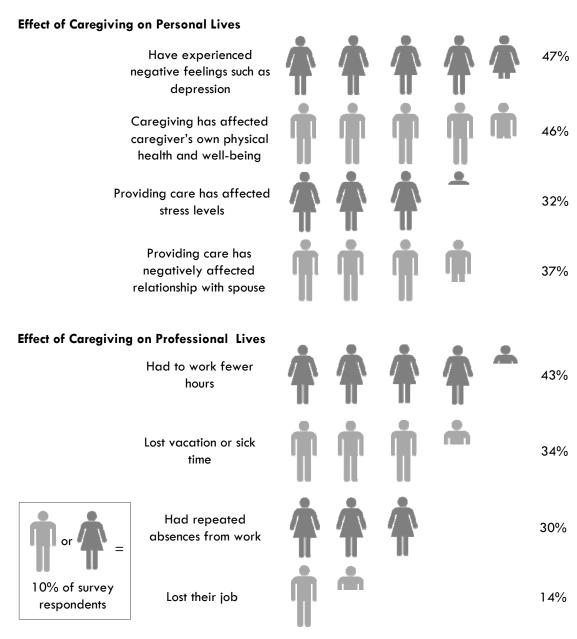
<sup>&</sup>lt;sup>2</sup> Redfoot, D., & Houser, A. (2010, September). More older people with disabilities living in the community: Trends from the National Long-Term Care Survey, 1984–2004. Washington, DC: AARP Public Policy Institute.

<sup>&</sup>lt;sup>3</sup> Redfoot, D., Feinberg, L., & Houser, A. (2013, August). The aging of the baby boom and the growing care gap: A look at future declines in the availability of family caregivers. Washington, DC: AARP Public Policy Institute.

decreased supply of caregivers will place greater demand on individuals who choose to keep their family members at home.

Caregiving responsibilities can weigh heavily on caregivers. A 2013 national survey of 899 caregivers assessed the effects of caregiving on their personal and professional lives.<sup>4</sup> On average, caregivers are providing care for 21 hours per week, and one-third of caregivers are providing care for more than 30 hours per week, as shown in Exhibit 1. Nearly half (47%) of caregivers experienced negative feelings such as depression and 43% of caregivers reported having to work fewer hours, thereby reducing their income.

Exhibit 1: Caregiving Can Negatively Affect the Personal and Professional Lives of Caregivers



Source: Program Evaluation Division based on data from Genworth's A Way Forward: Highlights from Beyond Dollars 2013.

<sup>&</sup>lt;sup>4</sup> Genworth. (2013, October). A Way Forward: Highlights from Beyond Dollars 2013.

Many states, including North Carolina, recognize that caregivers of adults with cognitive and/or physical impairments need respite, or temporary relief, from their caregiving responsibilities. The General Assembly defines respite as a service that is established to provide needed relief to unpaid primary caregivers who are

- caring for people 60 years of age or older or
- 60 years of age or older themselves and caring for persons who are age 18 or older, require constant supervision, and cannot be left alone either because of memory impairment, physical immobility, or other problems that render them unsafe alone.<sup>5</sup>

As defined by N.C. Gen. Stat. § 143B-181.10, respite care services include

- counseling and training in the caregiving role, including coping mechanisms and behavior modification techniques;
- counseling and accessing available local, regional, and state services;
- support group development and facilitation;
- assessment and care planning for the patient of the caregiver;
- attendance and companion services for the patient in order to provide release time to the caregiver;
- personal care services, including meal preparation, for the patient of the caregiver; and
- temporarily placing the person out of his or her home to provide the caregiver total respite when the mental or physical stress on the caregiver necessitates this type of respite.

As shown in Exhibit 2, the range of respite care programs varies depending on the level of care the recipient needs (e.g., assistance with activities of living versus skilled nursing care) and the amount of time they need that level of care (e.g., a few hours per day versus 24 hours a day).

Two divisions within the Department of Health and Human Services regulate providers of respite care.<sup>6</sup>

- Division of Aging and Adult Services. The Division of Aging and Adult Services is responsible for planning, administering, coordinating, and evaluating the activities developed under the federal Older Americans Act and the programs for older adults funded by the General Assembly. As part of its responsibilities, the division certifies and monitors adult day care and adult day health care facilities (see Exhibit 2).<sup>7,8</sup> Routine monitoring of compliance is performed by county departments of public health and social services.
- **Division of Health Service Regulation.** The Division of Health Service Regulation oversees medical, mental health, and adult care

<sup>&</sup>lt;sup>5</sup> N.C. Gen. Stat. § 143B-181.10.

<sup>&</sup>lt;sup>6</sup> In addition to these two divisions, the Division of Medicaid Assistance oversees respite services provided under its waivers, and the Division of Mental Health, Developmental Disabilities and Substance Abuse Services oversees respite services provided with state dollars.

<sup>&</sup>lt;sup>7</sup> The North Carolina State Standards for Certification are in 10A N.C. Admin. Code 06R.

<sup>&</sup>lt;sup>8</sup> In comparison, the Department of Health and Human Services's Division of Child Development and Early Education is responsible for licensing and monitoring all child care facilities.

facilities, emergency medical services, and local jails. It ensures that people receiving care in these facilities are safe and receive appropriate care. Through the State's Certification of Need process, the division also ensures that medical facilities are built only when there is a need for them. As part of its responsibilities, the division licenses and monitors 24-hour healthcare facilities including adult care homes, family care homes, hospitals, intermediate care facilities for individuals with intellectual disabilities, and nursing homes.

Because adult day care facilities provide services to elderly and disabled individuals during the day, they provide daytime respite to caregivers. Adult day care facilities must operate for a minimum of six hours each day for at least five days per week. Programs are required to have a full-time program director and must be self-contained with their own staff and separate areas. The Division of Aging and Adult Services has certified 100 adult day care facilities, collectively providing a total of 4,827 client slots, that operate under three different models:

- Adult day care programs (n = 30 facilities) provide an organized program of services during the day in a community group setting for the purpose of supporting the adults' personal independence and promoting their social, physical, and emotional well-being.
- Adult day health programs (n = 13 facilities) provide adult day care services and health care services under the supervision of nursing staff to all their participants. Programs are required to have a nurse on site a minimum of four hours per day or as long as necessary to provide the health care services needed by participants.
- Combination programs (n = 57 facilities) provide adult day care services to all their participants and health care services under the supervision of nursing staff to some of their participants.

Exhibit 2: Overnight Respite Pilot in Adult Day Care Facilities Adds to the Variety of Settings Offering Respite Services

Service Setting	Description	Highest level of care	Operating hours	Provides Daytime Respite	Provides Overnight Respite	Regulator
In-home services						
Home management	In-home aides assist individuals with non-personal care activities such as cooking, cleaning, laundry, and shopping to keep the individual safe in the home setting	No ADLs	Not 24 hours	<b>√</b>	<b>~</b>	Not regulated
Home care/ companion/sitter	Certified nurse aides assist individuals with personal care activities such as dressing, eating, personal hygiene, and walking to keep the individual safe in the home setting	ADLs	Not 24 hours	✓	<b>~</b>	DHSR
Home health	A home health agency furnishes the following services to an individual on a visiting basis in the home setting: part-time or intermittent nursing care; physical, occupational, or speech therapy; medical social services, home health aid services, and other therapeutic services; medical supplies and the use of medical appliances; and any of the foregoing services provided on an outpatient basis at a hospital, nursing home facility, or rehabilitation center	Skilled nursing	Not 24 hours	<b>~</b>	<b>~</b>	DHSR
Community-based se	ervices					
Group respite	A facility provides up to 6 hours per day/4 days per week of relief for the caregiver, socialization for the care receiver, and resource information for the family	No ADLs	Not 24 hours	<b>~</b>		Not regulated
Adult day care	A facility provides group care and supervision in a place other than an individual's usual place of abode on a less than 24-hour basis to adults who may be physically or mentally disabled	ADLs	Not 24 hours	<b>√</b>		DAAS
Adult day health care	A facility provides adult day care and offers health care services to adults under the supervision of nursing staff	Skilled nursing	Not 24 hours	<b>√</b>		DAAS
Institutional services						
Family care home	A facility provides 24-hour scheduled and unscheduled personal assistance to two to six residents; medication may be administered by designated, trained staff	Residential	24 hour	✓	<b>√</b>	DHSR
Adult care home/ assisted living	A facility provides 24-hour scheduled and unscheduled personal assistance to seven or more residents; medication may be administered by designated, trained staff	Residential	24 hour	<b>√</b>	<b>√</b>	DHSR
Nursing home/skilled nursing facility	A facility provides 24-hour nursing or convalescent care for three or more patients who are not acutely ill but have ailments for which medical and nursing care are indicated	Skilled nursing	24 hour	<b>√</b>	<b>√</b>	DHSR
ICF/IID	A facility provides 24-hour evaluation, planning, supervision, coordination, and integration of health or rehabilitative services to help individuals with intellectual disabilities function at their greatest ability	Intermediate	24 hour	<b>~</b>	<b>~</b>	DHSR
Hospital	A facility with organized medical staff provides health care, diagnostic and therapeutic services, and continuous nursing care under the supervision and direction of physicians to two or more persons over a period in excess of 24 hours	Acute	24 hour	<b>~</b>	<b>~</b>	DHSR
		•	•	•	•	•

Notes: ADLs stand for assistance with activities of daily living such as dressing, eating, personal hygiene, and walking. Skilled nursing care involves trained professionals performing custodial and skilled nursing care. Residential care is provided to individuals who do not need 24-hour nursing care but are unable to live independently. Intermediate care involves room and board and may include occasional or part-time skilled nursing care. Acute care is active but short-term treatment for a severe injury or episode of illness, an urgent medical condition, or recovery from surgery. ICF/IID (formerly ICF/MR) stands for Intermediate Care Facility for Individuals with Intellectual Disabilities. DAAS stands for the Division of Aging and Adult Services. DHSR stands for the Division of Health Service Regulation. Home management and group respite are not regulated, but providers must adhere to Home and Community Care Block Grant standards to receive funding.

Source: Program Evaluation Division based on data from General Statutes and the Department of Health and Human Services.

Two adult day health care facilities offered overnight respite before the service was regulated. In 2001, the Alzheimer's Association granted CarePartners \$40,000 to offer overnight respite. For one year, CarePartners offered the service with five beds for one weekend out of the month. Families were asked to contribute based upon ability to pay, but much of the cost was covered by the grant. During each weekend that CarePartners offered the service, three to five participants attended. Eventually, the Division of Aging and Adult Services informed CarePartners it had to discontinue the service because state law had not authorized the service at that time. In 2005, the Duke Endowment granted Life Enrichment \$206,540 to offer overnight respite. For eight months, Life Enrichment offered the service with six beds at a cost per night between \$120 and \$180. Over eight months, 48 individuals received overnight respite for a total of 182 nights. Eventually, the Division of Facility Services (now the Division of Health Service Regulation) issued Life Enrichment a cease and desist order to discontinue the service because it was not authorized.

The purpose of restricting facilities to authorized services is to regulate the service to ensure the safety of care recipients. In these instances, two adult day care facilities were providing 24 hours of care to a vulnerable population without an examination of whether additional safety precautions needed to be in place after daytime operating hours.

### Overnight Respite Pilot in Adult Day Care Facilities

In 2011, the General Assembly took an initial step toward offering a new respite service in the form of overnight care provided at adult day care facilities. Session Law 2011-104 (see Appendix A) authorized the Department of Health and Human Services (DHHS) to pilot an overnight respite program in adult day care facilities. The legislation directed DHHS to select a minimum of two and a maximum of four facilities at which to conduct the pilot. All pilot facilities had to be certified adult day care programs, and at least two of the facilities had to be operated by organizations that had been offering adult day care in North Carolina since 1980 and had received national recognition. 10

For the purposes of the pilot,

- participants were restricted to receiving overnight respite care (i.e., 24-hour care) for no more than 14 consecutive calendar days or 60 total calendar days during a 365-day period;
- facilities were restricted to designating no more than six beds for overnight respite care; and
- the State and Medicaid were restricted from paying for any overnight respite services through the pilot.

<sup>&</sup>lt;sup>9</sup> Pilot sites were exempt from adult care home licensure pursuant to Article 1 of Chapter 131D of the General Statutes and licensure under Chapter 131E and Chapter 122C of the General Statutes.

<sup>&</sup>lt;sup>10</sup> Legislation defined national recognition as including all of the following criteria: designated as a National Model Adult Day Care Center by the Robert Wood Johnson Foundation; designated as the only Teaching Day Center for recipients of North Carolina adult day care startup funds; received the North Carolina Non-Profit Center's Non-Profit Sector Stewardship Award for exemplary stewardship of resources; and received Leadership in Energy and Environmental Design (LEED) certification.

The legislation directed DHHS's Division of Health Service Regulation to approve and monitor overnight respite in adult day care facilities because the division regulates 24-hour facilities, and by providing overnight respite, participating adult day care facilities would become 24-hour facilities. The division was directed to adopt rules to include minimum requirements regarding program management, staffing, building specifications, fire safety, sanitation, nutrition, enrollment, medication management, and program activities.<sup>11</sup>

The legislation required the Division of Health Service Regulation to

- initially inspect pilot facilities for compliance with the rules,
- periodically collect data on the number of individuals served and the average daily census from pilot facilities,
- conduct monitoring visits of pilot facilities no less frequently than every six months, and
- investigate complaints made by pilot participants.<sup>12</sup>

In conjunction with its 2011 directive to DHHS to pilot overnight respite care in adult day care programs, the General Assembly mandated that the Program Evaluation Division determine the success of the pilot by October 2014. This report evaluates the pilot and the feasibility of continuing to provide overnight respite in adult day care programs.

## **Findings**

Finding 1. Participants, caregivers, pilot facilities, and the Department of Health and Human Services perceive the pilot to be successful, but only one pilot facility has consistently provided overnight respite.

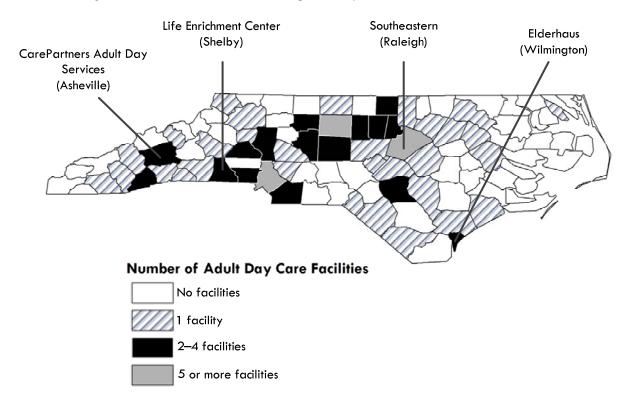
Session Law 2011-104 authorized a maximum of four pilot facilities to provide overnight respite service at adult day centers. The Division of Health Service Regulation administered an application process and selected the following four facilities for participation in the pilot:

CarePartners Health Services Adult Day Health/Day Care in Asheville, Elderhaus Adult Day Services in Wilmington, Life Enrichment Center Adult Day Care and Health Service in Shelby, and Southeastern Healthcare of North Carolina Adult Day Health in Raleigh (see Exhibit 3). All four facilities are combination adult day care and adult day health care programs.

<sup>&</sup>lt;sup>11</sup> The Division of Health Service Regulation based the rules for overnight respite in adult day care facilities on the rules for licensed family care homes, which provide residential care for two to six residents.

<sup>&</sup>lt;sup>12</sup> No complaints were made by pilot participants during the course of the pilot.

Exhibit 3: Adult Day Care Facilities and Overnight Respite Pilot Facilities in North Carolina



Source: Program Evaluation Division based on data from the Division of Aging and Adult Services.

As shown in Exhibit 4, three of the four pilot facilities have provided overnight respite services during the course of the pilot. Of these three pilot facilities, two (CarePartners and Southeastern) currently provide overnight respite, and one (Elderhaus) quit offering the service in May 2013. The fourth pilot facility (Life Enrichment) chose not to see any overnight clients during the pilot.

Exhibit 4: Utilization of Overnight Respite Services at Four Pilot Sites

Description	CarePartners (Asheville)	Elderhaus (Wilmington)	Southeastern (Raleigh)	Life Enrichment (Shelby)
General Facility Information				
Number of adult day clients enrolled as of June 2014	171 clients	43 clients	44 clients	237 clients
Overnight Respite Pilot Status				
Date authorized to provide overnight respite	January 2013	July 2012	March 2014	February 2013
Number of overnight respite beds authorized	4 beds	5 beds	6 beds	6 beds
Months offering overnight respite as of June 2014	16 months	10 months	1 month	0 months
Currently accepting overnight respite clients	Yes	No	Yes	No
Overnight Respite Clients				
Number of unique clients for overnight respite	39 clients	25 clients	2 clients	
Average clients per month for overnight respite	6 clients	5 clients	2 clients	
Overnight Respite Stays				
Number of nights overnight respite provided	256 nights	128 nights	7 nights	
Range of overnight respite stays	1-14 nights	1-14 nights	3-4 nights	
Number of unique stays for overnight respite	90 stays	42 stays	2 stays	
Average stays per month for overnight respite	6 stays	5 stays	2 stays	
Overnight Respite Costs				
Overnight respite start-up costs	Not available	\$20,000	\$148,039	\$250,000
Monthly operating costs for overnight respite	\$2,634	\$9,161	\$5,574	
Rate for overnight respite only (weeknights)	\$150	\$160	\$150	

Notes: CarePartners and Life Enrichment each operate two adult day care facilities. The facility at which overnight respite was or could have been offered is listed as the facility's city in the table. CarePartners has 45 day clients at its Henderson facility and 126 day clients at its Asheville facility. Life Enrichment has 136 adult day care clients at its Shelby facility and 101 day clients at its Kings Mountain facility. The rate for overnight respite in the table does not represent day services and does not reflect weekend rates, which vary across the facilities. The overnight rates for Southeastern and Life Enrichment assume the median level of care, whereas CarePartners and Elderhaus use a flat rate per night for overnight respite. Start-up costs for CarePartners were not available because of building modifications planned before the pilot, which were later changed to comply with the overnight respite rules developed by the Division of Health Service Regulation.

Source: Program Evaluation Division based on data provided by the four pilot facilities.

Among the three facilities that provided overnight respite during the pilot, differences exist regarding the time period during which the service was provided, the cost per night of the service, the number of clients served, and the number of nights the service was provided.

Pilot facilities differ regarding the date they began accepting
overnight clients. Nearly two years separate the dates on which
different pilot facilities saw their first overnight respite client.
Elderhaus first began offering overnight respite services in
September 2012, but the facility terminated the service as of May
2013. CarePartners began accepting clients in March 2013.
 Southeastern did not begin accepting overnight clients until May

2014. Both CarePartners and Southeastern continue to accept clients for overnight respite services.

Pilot facilities differ in the amount they charge for overnight respite services. The legislation authorizing the pilot describes overnight respite care as 24-hour care, and DHHS views overnight respite as a 24-hour program separate from adult day care programs. 13 However, each pilot facility was permitted to establish its own overnight respite rate; each facility chose to keep its daytime rate and add an overnight rate based on the services it provided in the time between when the adult day care program closed and when it re-opened the next morning. The rate charged per night varied depending on the day of the week and the client's acuity (level of attention required). 14,15 CarePartners charges overnight respite clients a flat rate of \$150 per night and limits the availability of the service to pre-determined weekends for cost containment purposes. Until recently, the facility required a minimum of two clients to be present at a given time for the service to be offered. 16 The rate Southeastern charges clients depends on the level of acuity: Level I clients are charged \$125 a night, Level II clients are charged \$150 a night, and Level III clients are charged \$175 a night. Elderhaus initially charged its overnight respite clients \$200 regardless of the day of the week but modified this charge to \$160 a night with an additional \$20 charge per hour beyond 24 hours on weekends.

During the course of this evaluation, the Program Evaluation Division learned the State operates four facilities that offer temporary overnight respite at substantially different rates than the adult day care facilities in the pilot. For example, the Greenwood Inn, located on the campus of Black Mountain Neuro-Medical Treatment Center, charges \$8 for 24 hours of respite care. In comparison, CarePartners, which is located 12 miles away in Asheville, charges \$55.75 for day services plus \$150 for overnight services for a total of \$205.75 for 24 hours of respite care. This issue is examined further in Appendix B.

• Pilot facilities differ in the number of clients seen for overnight respite. Although the overnight respite rules did not limit adult day care facilities to providing overnight respite only to their day clients, the pilot facilities chose to require any individuals seeking overnight respite services to first enroll in their adult day care program. The three facilities that provided overnight respite served a total of 66 clients between March 2013 and June 2014.

<sup>&</sup>lt;sup>13</sup> DHHS's rationale for considering adult day care programs as separate from the overnight respite services provided at adult day care facilities is based on the adult day care rule (10A N.C. Admin. Code 06R) requiring the area certified for adult day care to be used for the sole purpose of the adult day care program and its activities during hours of program operation.

<sup>&</sup>lt;sup>14</sup> Facilities' daytime rates on weekdays range from \$35 per day at Southeastern (Level I care) to \$61.75 per day at CarePartners (Level V care). Weekend daytime rates vary among facilities.

<sup>&</sup>lt;sup>15</sup> Although Life Enrichment never accepted clients, it established rates for its overnight respite service. Life Enrichment identified five levels of care, with corresponding charges of \$120 to \$180 per night, depending on acuity level.

<sup>&</sup>lt;sup>16</sup> In June 2014, CarePartners began offering the service on occasions when only one client is using the service and increased the rate on a case-by-case basis for these occasions.

CarePartners is the only facility to have seen overnight respite clients consistently throughout the pilot and has served the most clients (39 clients). Elderhaus saw the second largest number of clients (25 clients) but no longer offers the overnight service. Southeastern has provided overnight respite to 2 clients since May 2014.

 Pilot facilities differ in the number of nights they provided overnight respite services. CarePartners has provided overnight respite for the largest total number of nights (256 nights). Elderhaus provided overnight respite for a total of 128 nights in the 10 months it offered the service, whereas Southeastern has provided the service for a total of 7 nights in the 1 month it has offered the service.

Participants, caregivers, pilot facilities, and the Department of Health and Human Services perceive the overnight respite pilot to be successful. Session Law 2011-104 directed the Program Evaluation Division to assess the success of the pilot program as measured by four stakeholder groups: participants, caregivers, facilities, and the Department of Health and Human Services (DHHS).

Nearly 80% of participants were at least somewhat satisfied with the overnight respite services they received at adult day care facilities. The Program Evaluation Division surveyed caregivers at the two pilot facilities (CarePartners and Elderhaus) that saw clients through May 2014.<sup>17</sup> Because DHHS and pilot facility staff reported many adult day participants suffer from mental and physical impairments, caregivers rated their family member's satisfaction with the overnight services they received. As shown in Exhibit 5, (68%) of caregivers said their family member was "Very Satisfied" with the overnight services they received and 11% of caregivers reported their family member was "Somewhat Satisfied."

## Exhibit 5

Participants' and Caregivers' Reported Satisfaction with Overnight Respite Services They Received

	Perceived Satisfaction with Overnight Respite Services								
	Somewhat satisfied	Very satisfied							
Participants	5%	5%	11%	11%	68%				
Caregivers	0%	5%	0%	14%	81%				

Source: Program Evaluation Division based on survey of caregivers who used overnight respite at pilot facilities.

More than 95% of caregivers were satisfied with the overnight respite services provided by adult day care facilities. Caregivers also rated their own satisfaction with the overnight respite services provided. As shown in Exhibit 5, 81% of caregivers were "Very Satisfied" with the overnight services and 14% were "Somewhat Satisfied." Caregivers shared the following comments in the survey:

<sup>&</sup>lt;sup>17</sup> The Program Evaluation Division mailed 55 paper surveys to caregivers who used the service through May 2014 at CarePartners (n = 31) and Elderhaus (n = 24), asking for their own and their care recipient's perceptions of overnight respite care. Twenty-two caregivers returned surveys for a response rate of 40%.

 "I was very satisfied. I knew my mother was happy and well cared for by people who knew her and what her needs were and would do everything I would for her."

- "It has been a wonderful chance to get some work, family, and health issues taken care of. I love it and wish we could get more."
- "Having a break from caregiving gives me hope and allows me to recharge so I can continue as a caregiver."
- "If overnight services were not offered anymore, it would greatly increase my stress level which would also impact Dad's ability to stay at home."

Eighty percent of caregivers who used the service report they were at least somewhat likely to use the service again in the future.

All four pilot facilities would judge the pilot as successful in providing families another option in the continuum of respite care. The Program Evaluation Division interviewed directors of the four pilot facilities to determine their perceptions of the success of the pilot. Facility staff stated that before the pilot program began, caregivers desiring overnight respite relied on other family members to care for their loved ones, utilized assisted living and nursing facilities, took their loved ones to hospitals, or rearranged their plans to be able to care for their loved ones. Facility staff reported the pilot has been successful in adding a new service to the continuum of care for respite services.

According to pilot facility directors, participants' familiarity with facility staff is the primary benefit of allowing adult day care facilities to offer overnight respite. Responses to the caregiver survey reinforced this perception. For example, one caregiver wrote, "My Dad is used to going to Elderhaus so if they had overnight respite he would not be nearly as traumatized as he would be staying in a nursing home. As his caregiver, I would NEVER consider bringing him to a nursing home because he would be very confused and upset. However, if he could stay at Elderhaus at a place and with people he is familiar with, I would be VERY grateful for that service [emphasis in the original]."

Facility staff also point to the number of repeat customers, or customers who utilized the service on more than one occasion, as an indicator of the success of the pilot. The Program Evaluation Division attempted to measure this claim of success of the pilot objectively, beyond the method required by Session Law 2011-104, and the results of this analysis appear in Finding 2.

DHHS officials describe the pilot as successful in providing an additional value-added option for caregivers at the pilot facilities but realize success has been facility-specific. The Program Evaluation Division interviewed staff at the Division of Health Service Regulation and Division of Aging and Adult Services to determine their perceptions of the success of the pilot. Staff at these divisions reported that in general the pilot has been successful because it is providing families with another option for respite services; however, they also recognize the success of the pilot has varied between the four pilot facilities.

At the individual facility level, DHHS staff view CarePartners as successful, and stated Southeastern's success has yet to be determined because it just began accepting overnight clients in May 2014. DHHS staff believe they could have judged the success of Life Enrichment if the facility had seen overnight respite clients. DHHS officials did not comment on the success of Elderhaus, whose last overnight respite client was seen in May 2013. Overall, DHHS officials believe overnight respite should not be limited to the four pilot facilities, but rather that all adult day care facilities across the State should have the option to provide the service.

In summary, only one pilot facility (CarePartners) has consistently provided overnight respite care to clients, and only two pilot facilities (CarePartners and Southeastern) are currently offering overnight respite services to their adult day care clients. A total of 66 clients have received overnight respite services since the pilot began. The majority of participants and caregivers are satisfied with the services received. The four pilot facilities and DHHS officials believe the pilot has been successful in providing an additional option to families, but DHHS realizes the success of the pilot is hindered by the fact that only one facility has consistently offered the service.

Finding 2. The legislative mandate for the overnight respite pilot and the Department of Health and Human Services's implementation of the pilot only met two of the ten recommended components of a well-designed pilot program.

Pilot programs are new initiatives implemented on a small scale that are intended to provide data showing whether or not the new program has the potential to succeed on a larger scale. A 2008 Fiscal Brief posed 10 questions that policymakers should ask to ensure new pilot programs will be able to provide clear results. 18 The Program Evaluation Division determined how well each question can be answered with regards to the overnight respite pilot based on the implementation status of the recommended components of a well-designed pilot (see Exhibit 6). The legislation authorizing a pilot of overnight respite in adult day care facilities directed the Department of Health and Human Services (DHHS) to implement the pilot.

<sup>18</sup> Fiscal Research Division. (2008, August). Ten questions to better pilot programs. Fiscal Brief. Raleigh, NC: General Assembly.

#### Exhibit 6

Implementation Status of the Overnight Respite Pilot

Elements of a Well-Designed Pilot Program	Implementation Status
1. Problem statement defining the problem that needs solving	•
2. Conceptual framework demonstrating how the pilot program addresses the identified problem	1
3. Budget estimating the State's cost for the pilot program	•
4. Fiscal analysis estimating the State's cost for a full-scale program	•
5. Performance criteria assessing the program's success	0
6. Examination of whether alternative solutions could produce similar outcomes	0
7. Study design allowing for meaningful evaluation	0
8. Study design reducing threats to validity	0
9. Substantial time for observing program effects	•
10. Substantial units for observing program effects	1
● = Fully implemented;	nplemented

Source: Program Evaluation Division.

 What is the problem that needs solving? A clear problem statement defines the nature, magnitude, and distribution of the social problem targeted by a program.

The legislative mandate fully implemented a problem statement. The legislation authorizing the overnight respite pilot program states, "The population of adults who are elderly or disabled in North Carolina is expected to increase, thereby increasing the need for safe and available overnight respite care." This problem statement adequately defines the problem the pilot program was designed to address.

2. How does the program address the identified problem? A conceptual framework demonstrates a clear, logical, and unambiguous relationship between the problem and the remedies that are to be applied to the problem.

**DHHS partially implemented a conceptual framework.** The pilot's legislation explains that offering overnight respite services in adult day care facilities will address the increased need for safe and available overnight respite care for elderly and disabled adults because

- adult day care provides group care and supervision to adults who may be physically or mentally disabled;
- adult day care provides care and supervision during the day, allowing caregivers a time of respite or allowing caregivers to attend to other duties, including work; and
- adult day care allows individuals to remain in their communities and/or in familiar surroundings, thereby prolonging or eliminating the need for placement in a longterm care facility.

> Although these reasons provide insight into the General Assembly's rationale for authorizing the pilot program, the conceptual framework for the overnight respite pilot program would have been clearer had DHHS developed a logic model for the program. As suggested in previous Program Evaluation Division reports, logic models are tools that link program goals, activities, outputs, and outcomes in a way that helps define and describe how programs work and how they should be held accountable. 19 The Program Evaluation Division created a logic model to demonstrate how this approach could have been applied to the overnight respite pilot (see Exhibit 7).

<sup>19</sup> Program Evaluation Division. (2012, April). Contract agent vehicle registration and titling services are cost efficient, but contracts need performance terms. Report to the Joint Legislative Program Evaluation Oversight Committee. Raleigh, NC: General Assembly. Program Evaluation Division. (2011, October). Programs for children, youth, and families need a guiding framework for accountability and funding. Report to the Joint Legislative Program Evaluation Oversight Committee. Raleigh, NC: General Assembly. Program Evaluation Division. (2010, April). High school graduation project requirement should remain a local school district decision. Report to the Joint Legislative Program Evaluation Oversight Committee. Raleigh, NC: General Assembly.

**Exhibit 7: Logic Model for the Overnight Respite Pilot Program** 

### **Program Goal**

For adult day care facilities to address the increased need for safe and available overnight respite care for the elderly and disabled population

Inputs	Activities		Outputs		Outcomes
Resources to operate program	How goals are achieved	<b>&gt;</b>	Direct products of activities	7	Direct program benefits
1. DAAS staff	<ol> <li>DAAS staff certify adult day</li> </ol>		1. Number of pilot facilities that		1. Participant satisfaction
2. DHSR staff	care facilities		offer the service		2. Caregiver satisfaction
3. Adult day care facilities	2. DHSR staff create application to		2. Facility expenditures vs.		3. Pilot facility satisfaction
4. Caregivers	become a pilot facility		revenues for offering the service		4. DHHS satisfaction
	authorized to offer overnight		3. Number of caregivers that use		5. Percentage of day clients that used
	respite		the service		overnight respite
	3. Adult day care facilities apply		4. Number of separate occasions		6. Percentage of clients using overnight
	to be pilot facilities		that caregivers use the service		respite that used the service on more
	4. DHSR staff select pilot facilities		5. Number of nights caregivers use		than one occasion
	5. DHSR staff adopt rules for		the service		7. Average monthly bed utilization for
	program management, staffing,		6. Length of stay in which service		overnight respite service
	building specifications, fire		was used		8. Caregivers receive respite from
	safety, sanitation, nutrition,		7. Average clients per month		overnight care responsibilities
	enrollment, medication		8. Average number of stays per		9. Caregiver stress is reduced
	management, and program		month		10. Additional time caregivers keep their
	activities		9. Monthly operating costs for		family member in the community,
	6. Pilot facilities comply with rules		service		prolonging or eliminating the need for
	7. DHSR staff inspect pilot facilities		10. Rate charged to clients for		placement in long-term care facilities
	for compliance with rules and		service		
	authorize them to offer		11. Number of complaints		
	overnight respite		investigated		
	8. DHSR staff conduct monitoring		12. Number of monitoring visits by		
	visits of pilot facilities no less		DHSR staff		
	frequently than every six months				
	9. Caregivers pay for service				
	10. DHSR staff investigate				
	complaints made by caregivers				
	or participants				

Notes: DAAS stands for the Division of Aging and Adult Services. DHSR stands for the Division of Health Service Regulation.

Source: Program Evaluation Division.

3. Is there a budget or spending plan? A well-crafted budget shows the program has been thoroughly planned, aligns spending to the program's stated goals, and includes the resources necessary for successful implementation and evaluation.

**DHHS fully implemented a budget.** In May 2012, the Division of Health Service Regulation produced a fiscal impact analysis that estimated the cost to the State for monitoring the new overnight respite pilot program (see Exhibit 8). The division's spending plan adequately assessed the fiscal impact of the pilot program on state government.

#### **Cost Type** FY 2012-13 FY 2013-14 FY 2014-15 Construction review costs \$ 9,400 \$ 7,000 \$ 7,000 2,500 2,500 2,500 Inspection costs 11,900 \$ 9,500 \$ 9,500 Total

Source: Program Evaluation Division based on data from the Division of Health Service Regulation.

4. What is the cost of the program if it is successful? To keep costs manageable, pilot programs initially focus on a small target population or number of sites. However, a determination of full-scale program costs is necessary to determine if the program is feasible on a larger scale.

**DHHS** partially implemented a projection of full-scale program costs. As shown in Exhibit 9, the actual cost to the State for monitoring the four pilot facilities has totaled \$13,095 since the inception of the program, at an average cost of \$3,274 per facility. The actual costs of the pilot program were below those projected by the Division of Health Service Regulation because only one facility consistently provided overnight respite. The Division of Health Service Regulation did not estimate the State's cost for authorizing all adult day care facilities to offer overnight respite. The Program Evaluation Division surveyed non-pilot facilities to determine their interest in offering overnight respite services. Based on the average cost per facility (\$3,274) and the number of facilities interested in providing the service (n = 58), the Program Evaluation Division estimated that the full-scale cost of the program to the Division of Health Service Regulation would be \$189,892.

### Exhibit 8

State's Budgeted Costs for Monitoring Overnight Respite in Adult Day Care

#### Exhibit 9

State's Actual Cost for Monitoring Overnight Respite in Adult Day Care

Facility	Construction Review		Inspection	on Cost	Total	
CarePartners (Asheville)	\$	3,428	\$	691	\$	4,119
Elderhaus (Wilmington)		1,913		1,083		2,996
Life Enrichment (Shelby)		2,005		0		2,005
Southeastern (Raleigh)		3,644		331		3,975
Total	\$	10,990	\$	2,105	\$	13,095
Average per Facility	\$	2,748	\$	526	\$	3,274

Source: Program Evaluation Division based on data from the Division of Health Service Regulation.

5. What criteria will be used to determine the program's success or failure? Defining objective criteria against which to assess program performance is essential to interpreting the results of a pilot program.

**DHHS did not implement performance criteria.** The legislation authorizing the overnight respite pilot program simply required the Program Evaluation Division to measure success of the pilot based on the perceptions of participants, caregivers, facilities, and DHHS. The results of these subjective measures are presented in Finding 1.

As part of the pilot application, the Division of Health Service Regulation asked potential sites to describe the methods they would use to measure and maintain quality care.

- CarePartners stated it would use its annual caregiver survey and a discharge survey to evaluate customer satisfaction.
- Elderhaus stated it would survey participating caregivers monthly to ensure they were satisfied and would maintain a log of care recipients' responses to being verbally asked if they were satisfied with their stay.
- Life Enrichment stated it would use its annual caregiver satisfaction survey to evaluate customer satisfaction.
- Southeastern stated it would use its clinical record review process to determine the extent to which staff complied with accepted professional standards and principles.

The Division of Health Service Regulation did not follow up with any of the pilot sites to gather the performance information the facilities planned to collect. The Program Evaluation Division was able to obtain this information from CarePartners and Elderhaus. CarePartners's survey found that 100% of its caregivers were "very satisfied" with the service. Elderhaus's survey found that 100% of its caregivers deemed the overnight stay a "positive experience" and that 100% would utilize the service again.

To better assess the pilot's success, the Division of Health Service Regulation could have developed and collected standardized

performance measures from all of the pilot sites and specified the indicators of demand against which those sites would be assessed. As shown in Exhibit 10, the Program Evaluation Division identified three objective measures of the success of the pilot and established potential indicators of demand for these measures.

- Percentage of day clients that used overnight respite. The percentage of potential clients who utilized a service represents an indicator of demand for a service. For each facility with available data, the Program Evaluation Division divided the number of clients that used the overnight respite service over the course of the pilot by the total number of adult day care clients enrolled as of June 2014. Elderhaus provided overnight respite to more than half (58%) of its day clients, and CarePartners provided overnight respite to nearly a quarter (23%) of its day clients. Based on these two figures, a potential indicator of demand for this performance measure could be 40%.
- Percentage of clients that used overnight respite more than once. Utilization of a service on more than one occasion acts as an indicator of satisfaction with and demand for the service. For each facility with available data, the Program Evaluation Division divided the number of clients that stayed more than once (irrespective of how many nights they stayed) by the total number of clients that used the overnight respite service. More than half (62%) of clients who used overnight respite services at CarePartners used the service on more than one occasion. Nearly half (44%) of clients who used overnight respite services at Elderhaus used the service on more than one occasion when the service was being offered. Based on these two figures, a potential indicator of demand for this performance measure could be 50%.
- Average monthly bed utilization. Utilization of a service compared to the capacity to provide the service acts as an indicator of demand for the service. For each facility with available data, the Program Evaluation Division first determined the number of potential bed nights had all of the facility's overnight beds been filled every night of the month for the months the service was offered. Then, monthly bed utilization was calculated by dividing each month's actual bed nights (total number of beds filled each night of the month) by potential bed nights. Lastly, monthly bed utilization was averaged across the months the service was offered. CarePartners's overnight respite beds were utilized at 13% of their capacity, and Elderhaus's overnight respite beds were utilized at 9% of their capacity. Based on these two figures, a potential indicator of demand for this performance measure could be 10%.

Exhibit 10: Objective Measures of Pilot Success and Potential Indicators of Demand

Performance Measure	CarePartners (Asheville)	Elderhaus (Wilmington)	Southeastern (Raleigh)	Life Enrichment (Shelby)	Potential Indicator of Demand (based on two highest scores)
Percentage of enrolled day clients that used overnight respite	23%	58%	5%	N/A	40%
Percentage of clients using overnight respite that used the service more than once	62%	44%	N/A	N/A	50%
Average monthly bed utilization for overnight respite	13%	9%	2%	N/A	10%

Notes: Because Southeastern served its first overnight respite client in the last month of the time period examined, the facility's percentage of clients that used overnight respite more than once was not calculated; however, Southeastern staff revealed that one of its two clients in June 2014 has since used the overnight service a second time.

Source: Program Evaluation Division based on data provided by the four pilot facilities.

6. What alternative programs/solutions might also address the problem? Alternative programs, products, or services that address the same problem as the pilot program should be investigated to determine if they have a greater likelihood of success or can achieve similar results at less cost.

DHHS did not implement an examination of alternative solutions. DHHS does not have utilization or cost data on any providers of overnight respite. To determine what caregivers do when they need overnight respite care, the Program Evaluation Division surveyed all adult day care facilities across the State that were not involved in the pilot.<sup>20</sup> As shown in Exhibit 11, more than three quarters (79%) of adult day care facilities reported their caregivers receive overnight respite by finding other family members or friends to stay with their loved one. Other sources of overnight respite include paying a private sitter (66%) or temporarily sending their loved one to an assisted living facility (60%). Cost data on these options is not readily available. However, as an example, Raleigh's Resources for Seniors, Inc. has compiled a list of 19 assisted living facilities and 11 nursing homes that are willing to provide overnight respite for two weeks or less, and they charge rates between \$100 and \$200 a night.

<sup>&</sup>lt;sup>20</sup> The Program Evaluation Division administered an electronic survey to non-pilot facilities asking for their perceptions of the pilot and perceived demand for overnight respite using email addresses for each adult day facility obtained from the Division of Aging and Adult Services and the North Carolina Adult Day Services Association. Contact information was accurate for 84 of the 92 non-pilot facilities. The Program Evaluation Division received responses from 47 of these 84 non-pilot facilities for a response rate of 56%.

### Exhibit 11

Adult Day Care Providers Report Caregivers Are Most Likely to Receive Overnight Respite from Other Family Members or Friends

Provider of Overnight Respite	Estimated Utilization Rate
Family members or friends	79%
Private sitter	66%
Assisted living facility	60%
In-home assistance	47%
Nursing home	38%
Hospital	9%

Source: Program Evaluation Division based on survey of non-pilot adult day care facilities.

7. Does the design of the program allow for meaningful evaluation? A valid study design allows evaluators to determine whether the pilot program is producing the desired results.

**DHHS** did not implement a study design allowing for meaningful evaluation. The legislation authorizing the overnight respite pilot program used a satisfaction study design. As shown in Exhibit 12, this design is the least likely to allow for meaningful evaluation. DHHS did not take any steps to elevate the level of the study's design, such as identifying control facilities that closely matched the pilot facilities to create a comparison-group study or assessing caregiver stress before and after the overnight service was offered to create a pre-post study.

## Exhibit 12

Overnight Respite Pilot Was Designed as a Satisfaction Study

	Study Type	Study Description
evaluation	Randomized controlled trial	Units are randomly assigned to either the treatment group (take part in pilot) or control group (do not take part in pilot)
	Comparison- group study	Units are selected for either the treatment group or control group in an attempt to match the groups along an array of characteristics (e.g., demographics)
r meaningful	Pre-post study	Units are assessed on the same measures before and after the intervention (pilot service) to determine if they improved or regressed
Allows for	Poorly-designed comparison-group study	Units are selected for either the treatment group or control group, but the groups are not closely matched along an array of characteristics
	Satisfaction study	Units are assessed for their level of satisfaction

Source: Program Evaluation Division based on Fiscal Brief on Pilot Programs (2008).

In an attempt to elevate the overnight respite pilot from a satisfaction study to a poorly-designed comparison-group study, the Program Evaluation Division surveyed both caregivers who did and did not use the overnight respite service offered at the pilot facilities.<sup>21</sup> The Program Evaluation Division found four statistically significant differences between the two populations:<sup>22</sup>

- Overnight respite clients are older. Caregivers who used
  the overnight respite service take care of clients that are, on
  average, six years older than clients whose caregivers have
  not utilized the service (83 years old compared to 77 years
  old).<sup>23</sup> This result may indicate that caregivers of younger
  clients could be more likely to use the service as their
  affected family member ages.
- Overnight respite clients have higher household incomes.
   Although both users and non-users have an average household income between \$25,000 to \$74,999, more users of the overnight respite service fall in this category than those that did not use the service.<sup>24</sup> This result suggests those with greater financial means are better able to take advantage of overnight respite services.
- Caregivers using overnight respite are more stressed. A higher percentage of caregivers (57%) who used the overnight respite service reported they are often or always stressed about taking care of their family member compared to caregivers (45%) who did not use the overnight service. Respite is intended to provide temporary relief and rest from caring for an elderly or disabled family member. This result suggests caregivers who used the service are stressed more often, which may be why they sought out the service. A determination of whether receiving overnight respite reduces caregiver stress could only be determined from a randomized control trial, comparison group study, or pre-post study.
- Caregivers using overnight respite have been providing care longer. More than 95% of caregivers who used the

2

 $<sup>^{21}</sup>$  In addition to the previously discussed mail survey sent to caregivers at CarePartners and Elderhaus who use the overnight service, the Program Evaluation Division administered paper surveys to caregivers at CarePartners and Elderhaus that did not use the overnight respite service. During site visits to these facilities, the Division dropped off envelopes containing the survey and return self-addressed envelopes with pre-paid postage. The survey was distributed to caregivers by staff at CarePartners (n = 140 surveys) and Elderhaus (n = 43 surveys). The Division received 84 surveys of the 183 distributed for a response rate of 46%.

<sup>&</sup>lt;sup>22</sup> When comparing two groups, a statistically significant difference tells researchers the two groups differ from one another on a particular dimension for a reason other than random chance. Because of differing sample sizes for caregivers who did and did not use the service, the Program Evaluation Division used a Students t-test, assuming unequal variances and a 95% confidence interval where there is only a 5% chance of the effect occurring due to random chance. The small sample size limits the generalizability and statistical power of these differences; however, they are presented for exploratory purposes.

<sup>&</sup>lt;sup>23</sup> This difference was statistically significant at p < .05.

<sup>&</sup>lt;sup>24</sup> The survey asked caregivers their total household income, including any earnings from the individual receiving care, categorically along five dimensions; thus, a true average household income figure cannot be computed. This difference was statistically significant at p < .05.

<sup>&</sup>lt;sup>25</sup> This difference was statistically significant at  $\rho < .05$ .

overnight respite service have cared for their family member at home for five years or more, compared to 67% of caregivers who did not use the overnight service.<sup>26</sup> The fact that caregivers who used the service have cared for their family member at home longer may be a factor in why they sought out the service.

In addition to these factors, the Program Evaluation Division measured but did not find significant differences in care recipients' physical health, mental acuity, and ability to care for themselves.<sup>27</sup> Also caregivers did not differ significantly as to whether they felt they had options for overnight respite, they could keep up with their other responsibilities, or their own physical health was deteriorating because of providing care.<sup>28</sup>

8. Are there problems in the program design that will affect validity? A study should have internal validity—the intervention is causing the desired outcome—and external validity—the program is replicable, producing similar results in different settings. In this pilot program, the intervention was the provision of overnight respite at adult day care facilities.

DHHS did not implement a study design that limited threats to validity.

- Self-selection bias threatened the internal validity of the overnight respite pilot. Self-selection bias occurs when pilot programs are conducted only in places that have expressed a desire to participate in the program. For the overnight respite pilot, only 7 of the 100 adult day care facilities across the State applied to participate in the pilot. These facilities' decision to participate may be correlated with traits that make the desired outcome more likely. For example, facilities opting to offer a new service may be better equipped to absorb the initial financial losses associated with offering a new service. Indeed, Elderhaus reported losing a total of \$63,889 in offering overnight respite. A better approach would have been to randomly select four facilities to ask to participate in the pilot.
- A non-representative sample threatened the external validity of the overnight respite pilot. A nonrepresentative sample occurs when the units participating in the pilot program are not representative of the characteristics of the broader population that would be served under the full-scale program. Three of the four pilot facilities are located in North Carolina's 2<sup>nd</sup> (Raleigh), 8<sup>th</sup>

<sup>&</sup>lt;sup>26</sup> This difference was statistically significant at  $\rho < .05$ .

<sup>&</sup>lt;sup>27</sup> Caregivers rated clients' physical health, mental acuity, and ability to care for self on a 5-point scale (poor, fair, good, very good, excellent).

<sup>&</sup>lt;sup>28</sup> Caregiver feelings were based on frequency of thoughts (never, rarely, sometimes, often, always); caregivers that did not use overnight respite were asked for frequency of thoughts for the last month in which they cared for their family member at home, and caregivers that used overnight respite were asked for their thoughts for the last month in which they used overnight respite.

(Wilmington), and 10<sup>th</sup> (Asheville) largest cities, respectively. A better approach would be to identify the important characteristics that differentiate adult day care facilities (e.g., urban vs. rural, percentage of clients that are Medicaid eligible) and select pilot sites that represent the larger population based on those characteristics.

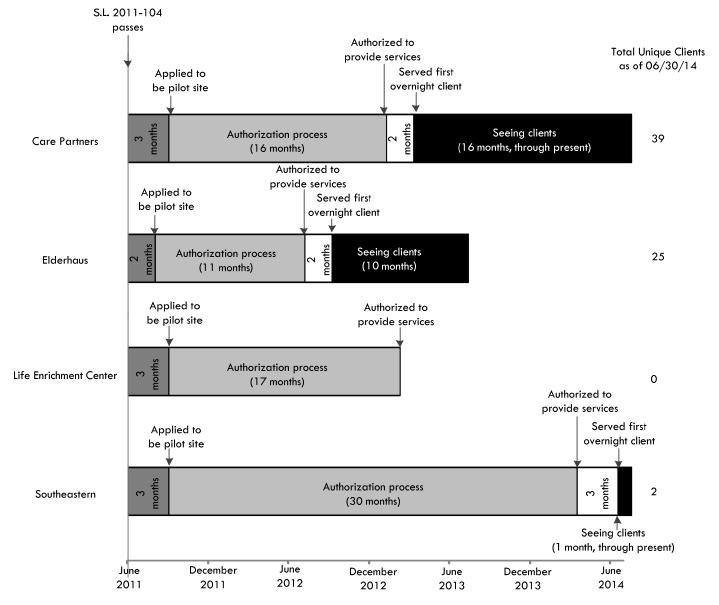
9. Is there sufficient time to observe effects? Substantial time is necessary to allow an intervention to work and to gather a sufficient number of observations.

The legislative mandate partially implemented substantial time to observe effects. The legislation authorizing the overnight respite pilot program became effective June 2011 and required the Program Evaluation Division to report on the pilot three years later by October 2014. As shown in Exhibit 13, the first year of the pilot was spent in selecting and approving facilities for offering the service.

The authorization process ranged from 11 to 30 months for the four pilot facilities. One of the reasons the facilities cited for delays in this process was facility renovations to adhere to the overnight respite rules, 29 which were based on the rules governing 24-hour family care homes. Although the overnight respite rules did not specifically require separate spaces for providing adult day care services and providing overnight respite services, according to DHHS, meeting all of the overnight construction requirements within the existing adult day care space would be difficult. Indeed, only one facility (Elderhaus) was able to adapt its current adult day care facility without major renovations to meet the overnight construction requirements. CarePartners incorporated the overnight respite construction requirements into a major renovation already underway, and Life Enrichment and Southeastern built new facilities with the overnight respite construction requirements in mind.

Based on the shortest approval and authorization processes experienced by Elderhaus, the pilot program had, at most, two years in which to collect client data for one facility. Had all four pilot facilities offered the service during that two-year timeframe, there may have been sufficient time to observe effects. As mentioned earlier, Elderhaus only offered the service for ten months, Life Enrichment never offered the service, and Southeastern did not offer the service until May 2014. Only CarePartners provided the service for a significant portion (16 months) of the available timeframe.

Exhibit 13: Timeframe for Applying as a Pilot and Serving Overnight Clients



Note: The authorization process involved the Division of Health Service Regulation determining each facility's construction requirements, the facility meeting those requirements, and the division inspecting the facility to ensure the requirements were met.

Source: Program Evaluation Division based on data provided by the Division of Health Service Regulation and pilot facilities.

10. Are there enough units of study to ensure statistical significance? A sufficiently large sample size is necessary for a study to demonstrate statistical significance.

The legislative mandate partially implemented substantial units to observe program effects. The legislation authorizing the overnight respite pilot program limited the study to four sites. Offering overnight respite at 4 out of 100 adult day care facilities may not have provided enough cases to determine effects. Ultimately, only one pilot site offered the service consistently throughout the study period, which further limited the statistical power of the pilot. Having more units to analyze increases the

confidence with which one can claim outcomes are the result of the pilot as opposed to the result of chance. Generally, a pilot should include a sample size that is sufficient to ensure meaningful statistical conclusion.<sup>30</sup>

The University of North Carolina at Chapel Hill's School of Government could be a useful resource to state agencies tasked with implementing pilots. The overnight respite pilot is not the only pilot design the Program Evaluation Division has found could not provide valid policy guidance. The Program Evaluation Division found similar issues with the legislatively mandated pilot of online driver education instruction in five local education agencies. After the Department of Public Instruction engaged the School of Government to conduct a comprehensive study of the available data, the School of Government noted several problems with the design of the department's pilot. As a result, the Program Evaluation Division recommended that state agencies and institutions initiating pilot projects at the direction of the General Assembly adhere to standards established by the School of Government.

In summary, several issues with the overnight respite pilot's design inhibited the Program Evaluation Division's ability to evaluate the success of the program. The Program Evaluation Division found only two of the 10 elements of well-designed pilots allowing for meaningful evaluation were fully implemented. The legislative mandate and DHHS both contributed to this limited capacity to evaluate the success of the pilot. The Program Evaluation Division identified ways to improve the eight elements that were only partially implemented or not implemented at all should the pilot be continued. Further, state agencies implementing pilots in the future could find the School of Government a useful resource.

## Finding 3. The legislative prohibition against using state or Medicaid funding for overnight respite in adult day care facilities hindered the effectiveness of the pilot.

The legislation authorizing the overnight respite pilot program prohibited the State and Medicaid from paying for any overnight respite services offered through the pilot.<sup>32</sup> According to stakeholders, the prohibition against using public funding for overnight respite hindered the ability of

<sup>&</sup>lt;sup>30</sup> Because only one of the pilot facilities continuously offered overnight respite, the Program Evaluation Division's survey of caregivers that used overnight respite only had a sample size of 22. The Program Evaluation Division determined a sample size of 354 caregivers would be necessary to be 95% confident that any findings are not the result of chance. This estimate is based on multiplying the average number of day clients at the four pilot facilities (n = 88, which only includes the Asheville facility for CarePartners and the Shelby facility for Life Enrichment) by the number of adult day care facilities across the State (n = 100) and an assumption of a 40% response rate (which is based on the response rate obtained by the Program Evaluation Division's survey of caregivers who used overnight respite).

<sup>&</sup>lt;sup>31</sup> Program Evaluation Division. (2014, March). Performance measurement and monitoring would strengthen accountability of North Carolina's Driver Education program. Report to the Joint Legislative Program Evaluation Oversight Committee. Raleigh, NC: General Assembly.

<sup>&</sup>lt;sup>32</sup> Although 39% of Home and Community Care Block Grant money comes from the federal government, once it is combined with the General Assembly's appropriation for the program, the Department of Health and Human Services considers it state money for the purposes of prohibiting its use for overnight respite in adult day care facilities.

the pilot facilities to offer the service and the ability of caregivers to utilize the service.<sup>33</sup>

- Department of Health and Human Services (DHHS). In interviews with staff from the Division of Health Service Regulation and the Division of Aging and Adult Services, lack of public funding was cited as a barrier to the provision of overnight respite in adult day care facilities. Staff stated that if there had been a guaranteed source of income, the facilities would have been more likely to market the service and families would have been better able to understand it as a service option.
- Adult day care facilities. In interviews with directors of the four pilot sites, all four facilities cited the lack of public funding as a barrier for adult day care facilities to provide overnight respite. For example, one facility director stated, "The legislation only addressed one side of the problem. It provided us with the availability of the service but no means for caregivers to take advantage of the service." The primary reason Life Enrichment never offered overnight respite was because of the prohibition of state and Medicaid funding. The two facilities not currently providing the service (Elderhaus and Life Enrichment) stated they would offer overnight respite if Medicaid funding was available.

Facility staff also claim use of the service would have been higher without funding restrictions. In a survey of non-pilot facilities, the Program Evaluation Division asked for the reasons the facilities did not apply to be included in the pilot program. Approximately 18% of non-pilot facilities responded they did not apply because they thought their adult day care clients could not afford overnight respite.<sup>34</sup>

• Caregivers. In a survey of caregivers who used overnight respite services offered at the pilot facilities, the Program Evaluation Division asked caregivers to describe any barriers they experienced in using overnight services. One caregiver stated, "I wish there were help paying for the overnight respite. We can't afford to use the respite as much as we like." In a Program Evaluation Division survey of caregivers who did not use overnight respite services offered at the pilot facilities, caregivers reported why they did not use the service. The most frequently reported reason for not using the service was the caregiver did not need overnight respite services (44%) followed by the cost of the

<sup>&</sup>lt;sup>33</sup> Although the legislation authorizing the overnight respite pilot program only prohibited state and Medicaid funding, the Division of Aging and Adult Services told CarePartners it could only use a federal LifeSpan Respite grant for daytime respite services, not overnight respite services. Thus, some stakeholders perceived the legislation as prohibiting public funding more broadly than simply state and Medicaid funding. However, the Department of Health and Human Services now understands the legislation to only prohibit state and Medicaid Funding. Thus, the department sees no issue with Southeastern's application for a City of Raleigh grant to fund overnight respite for one bed for one year.

<sup>&</sup>lt;sup>34</sup> Other reasons facilities did not apply for the pilot included staff costs being too great (30%), no desire to offer the service (25%), lack of demand for the service from day clients (16%), not knowing about the pilot (16%), not meeting the requirements to participate (14%), uncertainty about the facility's financial stability if offering the service (11%), not being in operation when the pilot began (11%), no state funding for the overnight service (2%), and no Medicaid funding for the overnight service (2%).

overnight service at the facility (24%). Caregivers also were asked how likely they would be to use the overnight respite service at the facility if the costs were lower. Over three-fourths (77%) of caregivers reported they would be more likely to use the overnight respite service if the costs were lower. One caregiver stated, "I know it is costly (to the facility) but on a fixed budget it is just too much to fit in at this time."

Although the pilot legislation prohibited state and Medicaid funding from paying for overnight respite at adult day care facilities, several public funding sources reimburse for respite in a home or institutional setting. Overnight respite at adult day care facilities (as authorized by the legislative pilot) represents a small segment of the continuum of available respite services to those providing care for their disabled or elderly family members. This service is also available from several other types of respite providers, such as home health agencies and assisted living facilities. Because the services provided and mechanisms by which these services are funded vary depending on the level of care and type of respite provider, the Program Evaluation Division only considered the primary sources of funding for respite services at adult day care facilities. As shown in Exhibit 14, adult day care facilities can receive reimbursement from Medicaid waiver programs for providing personal assistance or daytime supports during the day or from other public funding sources for providing daytime respite.

Exhibit 14: Public Funding Sources for Adult Day Care Facilities

Funding Source	Respite Reimbursement Rates	Adult Day Care Facilities Can Receive Reimbursement for <u>Daytime</u> Respite	Other Facility Types Can Receive Reimbursement for <u>Overnight</u> Respite
Medicaid's Community Alternatives Program for Disabled Adults (CAP-DA)	<ul> <li>In-home billed at a maximum of \$3.47 per 15-minute increment</li> <li>Institutional billed at a maximum of \$206.98 per day</li> </ul>	No, but they can receive reimbursement for providing personal assistance (adult day health care facilities only)	Yes
Medicaid's North Carolina Innovations (NC Innovations)	<ul> <li>Individual billed at a maximum of \$3.88 per 15-minute increment</li> <li>Group setting billed at a maximum of \$3.00 per 15-minute increment</li> <li>Community facility billed at a maximum of \$240.09 per day</li> </ul>	No, but they can receive reimbursement for providing day support services (adult day health care facilities only)	Yes
Medicare and Medicaid's Program of All-Inclusive Care for the Elderly (PACE)	Determined by capitated managed care programs	No, but they can receive reimbursement for providing personal assistance and/or day support services (adult day health care facilities only)	Yes
Home and Community Care Block Grant (HCCBG)	Reimbursement rates not predetermined but rather issued on an individual basis depending on what the provider charges	Yes	Yes
Family Caregiver Support Program	Reimbursement rates not predetermined but rather issued on an individual basis depending on what the provider charges	Yes	Yes
Veterans Health Administration's Standard Medical Benefits Package	<ul> <li>Non-institutional billed at a maximum of \$15 per day</li> <li>Institutional billed at a maximum of \$97 per day</li> </ul>	Yes (adult day health care facilities only)	Yes

Notes: Personal assistance services and day support services are provided to individuals who demonstrate unmet needs for qualifying activities of daily living, which include eating, dressing, bathing, toileting, and mobility.

Source: Program Evaluation Division based on information from the Department of Health and Human Services.

Medicaid's Community Alternatives Program for Disabled Adults (CAP-DA). This program waives certain North Carolina Medicaid requirements to furnish an array of home- and community-based services to adults with disabilities 18 years of age and older who are at risk of institutionalization. CAP-DA waiver services include respite care, which is defined as temporary support to the client's primary unpaid caregiver(s) by taking over the tasks of the caregiver(s) for a limited time. Respite care may be used for a wide range of needs, including family emergencies, planned absences (such as vacations, hospitalizations, or business trips), or relief from the daily responsibility and stress of caring for a special needs person. Respite is available in the client's home (billed at a maximum of \$3.47 per 15-minute increment) or in an institution that is licensed to provide the appropriate level of care (billed at a maximum of \$206.98 per day). Although adult day

health care facilities cannot receive reimbursement for providing respite care, they can receive reimbursement for providing personal assistance to CAP-DA participants.<sup>35</sup>

- Medicaid's North Carolina Innovations (NC Innovations, formerly Cap-MR/DD). This waiver is a resource for funding services and supports for people with intellectual and other related developmental disabilities who are at risk for institutional care in an Intermediate Care Facility for Individuals with Intellectual Disabilities. Waiver services include respite care, which is defined as periodic support and relief to the primary caregiver(s) from the responsibility and stress of caring for the beneficiary. Respite care may be used for planned or emergency events. Respite may include in- and out-of-home services, inclusive of overnight, weekend care, or emergency care. Respite is available for one individual at a time (billed at a maximum of \$3.88 per 15-minute increment), in a group setting that is licensed to provide the appropriate level of care (billed at a maximum of \$3.00 per 15-minute increment), or in a community facility that is licensed to provide the appropriate level of care (billed at a maximum of \$240.00 per day).36 Although adult day health care facilities cannot receive reimbursement for providing respite care, they can receive reimbursement for providing day supports to NC Innovations participants.37
- Medicare and Medicaid's Program of All-Inclusive Care for the Elderly (PACE). PACE is a capitated managed care program for the frail elderly that combines Medicaid and Medicare funding to serve persons who meet the State Medicaid Plan's requirements for coverage of nursing facility services. PACE facilities are required to provide all Medicaid-covered services as specified in the Medicaid Plan, which would include institutional and home-based respite. Although adult day health care facilities cannot receive reimbursement for providing respite care, they can receive reimbursement for providing personal assistance and day supports. Reimbursement rates are determined by the managed care organizations running each PACE program.
- Home and Community Care Block Grant (HCCBG). This grant
  consolidates local, state, and federal funding targeted at homeand community-based services intended to meet the unique service
  needs of older adults in their communities. Grant funds can be used
  for 18 purposes, including group and institutional respite. Group

<sup>&</sup>lt;sup>35</sup> Personal assistance is provided to individuals residing in a private living arrangement or a residential facility licensed by the State of North Carolina. These services are available to individuals who have a medical condition, disability, or cognitive impairment and demonstrate unmet needs for at least three of five qualifying activities of daily living with limited hands-on assistance for two activities of daily living, one of which requires assistance at the full dependence level. The five qualifying activities of daily living are eating, dressing, bathing, toileting, and mobility.

<sup>&</sup>lt;sup>36</sup> These rates are the rates established by Cardinal Innovations. According to the Division of Medical Assistance, most local management entities/managed care organizations have adopted these rates under the division's B-3 waiver.

<sup>&</sup>lt;sup>37</sup> Day supports are habilitation/support services, such as assistance with acquisition, retention, or improvement in self-help and assistance with socialization and adaptive skills in a non-residential setting.

respite is defined as the provision of respite care in a safe setting, operated on a scheduled basis for a period of up to six hours a day, where caregivers can take their family members who do not require personal (hands-on) care in order to get a break from their caregiving responsibilities. Institutional respite is defined as the temporary placement of an older adult who requires constant care and/or supervision out of his/her home to provide the unpaid, primary caregiver relief from caregiving responsibilities. Reimbursement rates are not predetermined by the grant program but rather are issued on an individual basis depending on what the provider charges. Adult day care facilities can receive reimbursement for providing institutional respite to HCCBG participants during daytime hours.

- Family Caregiver Support Program. The National Family Caregiver Support Program provides grants to states to fund a range of supports that assist caregivers in an effort to help them care for their family member at home for as long as possible. In North Carolina, this program provides services locally through 17 Area Agencies on Aging, including respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities. Eligible caregivers include those providing care for an older adult age 60 or older, those providing care for a person with Alzheimer's disease or related brain disorder, or those who are not the birth or adoptive parent (age 55 or older) raising a related child age 18 and under or an adult with a disability. Reimbursement rates are not predetermined by the program but rather issued on an individual basis depending on what the provider charges. Adult day care facilities can receive reimbursement for providing respite to program participants during daytime hours.
- Veterans Health Administration's Standard Medical Benefits Package. This benefits package provides all the necessary inpatient hospital care and outpatient services to promote, preserve, or restore veterans' health. The benefits package includes respite care, which is defined as services provided to veterans in inpatient, outpatient, or home settings while their caregivers take a break (e.g., to run errands or go out of town for a few days). Respite care is for veterans that need skilled services, case management, and assistance with activities of daily living (e.g., bathing or getting dressed) or instrumental activities of daily living (e.g., fixing meals and taking medicines); are isolated; or whose caregiver is experiencing burden. Based on their serviceconnected disability status and financial information, veterans may be charged a copay for non-institutional respite (billed at a maximum of \$15 per day) and institutional respite (billed at a maximum of \$97 per day). Adult day health care facilities can receive reimbursement for providing non-institutional respite to veterans during daytime hours.

None of these funding sources are currently authorized to reimburse adult day care facilities for overnight respite. If the General Assembly was to authorize overnight respite at all 100 adult day care facilities, the total Medicaid cost is estimated to be between \$198,000 and \$480,000 annually. The State's share of this total cost (35%) is estimated to be between \$69,300 and \$168,000 annually. The General Assembly decide to allow only the four adult day care facilities in the pilot to collect Medicaid funds, the total annual cost is estimated to be between \$7,920 and \$19,200. The State's share of this total cost (35%) is estimated to be between \$2,272 and \$6,720 annually. Some of these costs may be offset by savings to Medicaid if receiving overnight respite services at adult day care facilities delays institutional placement of Medicaid-eligible individuals. The methodology behind these estimates is detailed in Appendix C.

In summary, the legislation authorizing the overnight respite pilot program prohibited the State and Medicaid from paying for any overnight respite services offered through the pilot. According to DHHS, facilities, and caregivers, the prohibition against using state and Medicaid funding for overnight respite hindered the ability of the pilot facilities to offer the service and the ability of caregivers to utilize the service. Several public funding sources are authorized to reimburse for respite provided in the home or in an institutional setting. These same funding sources already reimburse adult day care facilities for other services, such as personal assistance and day supports, or for daytime respite. However, authorizing Medicaid to reimburse overnight respite services in adult day care facilities would create additional costs for the State.

## Finding 4. Although organizations affiliated with respite care have anecdotal evidence supporting the need for overnight respite services, none have empirical data on its demand.

The only national data available on overnight respite at adult day care facilities comes from a 2010 study of 557 adult day care facilities, which found 12% of them offer overnight respite.<sup>39</sup> The Program Evaluation Division attempted to obtain evidence of the need for overnight respite from a number of state sources, including the Department of Health and Human Services (DHHS), associations that represent caregivers and care recipients, and associations representing organizations that provide overnight respite.

The need for overnight respite services in North Carolina is unclear because no stakeholder organizations have specifically and quantitatively addressed the demand for this service. The Program Evaluation Division solicited data on the need for overnight respite in North Carolina from a number of sources, including DHHS, the North Carolina Respite Care Coalition, AARP North Carolina, and five organizations

<sup>&</sup>lt;sup>38</sup> Authorizing reimbursement should not increase the cost of the Home and Community Care Block Grant and the Family Caregiver Support Program because clients have a maximum budget they can spend on approved services.

<sup>&</sup>lt;sup>39</sup> MetLife. (2013). The MetLife National Study of Adult Day Services: Providing Support to Individuals and Their Family Caregivers, October 2010.

representing providers of overnight respite (see Exhibit 15). None of these organizations could provide data or reference empirical studies supporting claims for the demand for overnight respite services in North Carolina.<sup>40</sup>

Although unable to demonstrate the demand for overnight respite services empirically, several stakeholder organizations support the additional option of overnight respite at adult day care facilities. DHHS stated during interviews that although they have not conducted a formal needs assessment, they believe there is a need for overnight respite. DHHS staff noted the benefits of overnight respite at adult day care facilities in comparison to other providers, such as the familiarity of participants with the adult day care facility and the continuity of care for participants who are already there for day services and stay for overnight services. The North Carolina Adult Day Services Association reports overnight respite is a requested service both in this State and across the nation and consequently supports offering the service in adult day care facilities.

The North Carolina Respite Care Coalition stated it supports offering overnight respite in adult day cares because the need for respite services will only increase in the coming years and caregivers deserve options for obtaining respite care. Other organizations (AARP North Carolina, Association for Home Health and Hospice Care of North Carolina) do not object to adult day care facilities providing temporary overnight respite because increased caregiver flexibility may increase the length of time caregivers keep family members at home.

<sup>40</sup> The Division of Aging and Adult Services and the Division of Medical Assistance have provider reimbursement data on the type and costs of respite services, but neither collects data that could demonstrate utilization rates for overnight respite.

Exhibit 15: Stakeholders' Claims on the Need for Overnight Respite are Anecdotal

Stakeholder Category	Source	Membership	Perception of Demand for Overnight Respite	General Perception of Overnight Respite at Adult Day Care Facilities	Empirical Data on Demand
State regulators of respite providers	DHHS Division of Aging and Adult Services	State agency	Important option	In favor	None
respire providers	DHHS Division of Medical Assistance	State agency	Important option	In favor	None
Associations representing caregivers and care	NC Respite Care Coalition	Caregivers, respite providers, others interested in respite	Important option	In favor	None
recipients	AARP NC	Citizens age 50 and above	Important option	No objection	None
	Association for Home and Hospice Care of NC	Home health agencies, in-home aide providers	Important option	In favor	None
	NC Adult Day Services Association	Adult day facilities	Important option	In favor	None
Associations representing respite providers	NC Assisted Living Association	Assisted living facilities and vendors	In demand	Opposed, encourage using state resources to educate consumers that these services are already available from assisted living facilities	None
p	NC Association of Long Term Care Facilities	Assisted living facilities, family care homes	In demand	Opposed, emphasize adult day care facilities should comply with same rules as assisted living facilities if they want to provide overnight respite	None
	NC Health Care Facilities Association	Skilled nursing facilities	In demand	No objection	None

Notes: For "Perception of Demand for Overnight Respite," "In demand" indicates organizations believe overnight respite is needed by caregivers and "Important option" indicates organizations believe it is important for caregivers to have additional options for overnight respite. For "General Perception of Overnight Respite at Adult Day Care Facilities," "In favor" indicates organizations support overnight respite at adult day care facilities, "No objection" indicates organizations do not take issue with the service at adult day care facilities, and "Opposed" indicates organizations take issue with the service.

Source: Program Evaluation Division based on information provided by respite stakeholders.

Two organizations representing overnight respite providers are opposed to adult day care facilities providing overnight respite services.

The North Carolina Assisted Living Association believes adult day care

The North Carolina Assisted Living Association believes adult day care facilities are seeking to provide 24 hours of care on an ad hoc basis without being held to the same quality and safety regulatory standards as assisted living facilities, which already provide overnight respite services.

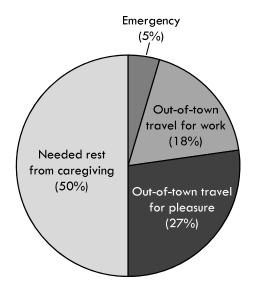
According to the association, a more cost-effective way to use state resources would be to educate consumers on services that are already available. The North Carolina Association of Long Term Care Facilities believes the rules governing overnight respite at adult day care facilities should be more similar to those governing assisted living facilities because both facility types would be providing 24-hour care.

There is limited empirical data to support the demand for overnight respite. The Program Evaluation Division attempted to quantify demand through surveys of caregivers who used the service, caregivers who did not use the service, and adult day care facilities that did not participate in the pilot. These surveys provide limited support of demand for the service, but these findings may not be generalizable because of the small sample size and other threats to validity.

• The primary reason caregivers used overnight respite services at adult day care facilities was for their own rest, and 100% of caregivers who used the service reported it reduced their stress. Caregivers who used the overnight respite services offered at two pilot sites—CarePartners and Elderhaus—provided their reasons for using the service. As shown in Exhibit 16, half of caregivers reported their primary objective in using overnight respite services was for their own rest (50%). All caregivers who used overnight respite services agreed that the service reduced their stress.

## Exhibit 16

Primary Reason Caregivers Use Overnight Respite At Adult Day Care Facilities is for Their Own Rest



Source: Program Evaluation Division survey of caregivers that used overnight respite at pilot facilities.

 More than 75% of caregivers who use daytime respite services at adult day care facilities report they are somewhat likely or very likely to utilize the service in the next year. This anticipated use could indicate it is the first time the caregiver has needed overnight respite or could indicate the caregiver was not aware of the service prior to the survey.

 More than 80% of adult day facilities that did not participate in the pilot reported overnight respite is an important part of the continuum of respite care, and almost all reported overnight respite is in at least moderate demand at adult day care facilities. Over half (57%) of directors of non-pilot adult day care facilities believe overnight respite is "Very Important" in the continuum of respite care.

The survey also asked non-pilot facilities to estimate the demand for receiving overnight respite from adult day care facilities. A majority (81%) stated the demand for the service at adult day care facilities is moderate, high, or very high. In addition, non-pilot facilities estimated that 17% of their current day clients would utilize the service if it were offered and that potential overnight clients would stay an average of five times in the next year, with an average stay of four nights during each stay.

In summary, there is no existing empirical data to support claims for the necessity of overnight respite in general or within adult day care facilities. Neither DHHS, associations representing caregivers and care recipients, nor associations representing respite providers collect data on the need for overnight respite, but they all claim the need exists. The Program Evaluation Division attempted to quantify this need through surveys of caregivers who used the service at adult day care facilities, caregivers who did not use the service at these facilities, and non-pilot adult day care facilities across North Carolina. These surveys show there is a perceived need for overnight respite; however, the generalizability of these findings is limited because of the small number of respondents and potential for response bias.

## Recommendations

Recommendation 1. The General Assembly should allow the pilot program authorizing overnight respite services in adult day care facilities to expire on June 1, 2015, as set out by its establishing legislation.

The Program Evaluation Division recommends the pilot expire, thereby ceasing the provision of overnight respite services in adult day care facilities, on its intended date based on the following reasons:

- Although the pilot is perceived as successful by participants, caregivers, facilities, and the Department of Health and Human Services (DHHS), only one adult day care facility consistently provided overnight respite services during the pilot (see Finding 1).
- The legislative mandate for the overnight respite pilot and its implementation by DHHS only met two of the ten recommended components of a well-designed pilot program (see Finding 2).
- No evidence exists to demonstrate the demand for overnight respite services at adult day care facilities and thus removing funding restrictions for this service may not be the best use of limited Medicaid resources (see Finding 3).

 DHHS and stakeholder associations cannot provide empirical data demonstrating the demand for overnight respite in adult day care facilities and thus must rely on anecdotal evidence of its need (see Finding 4).

The Program Evaluation Division recommends letting the pilot expire as set out by its establishing legislation. Other options regarding the provision of overnight respite in adult day care facilities were considered during this evaluation. Appendix D examines each of these options in detail:

- extend the pilot and allow the current pilot facilities to collect state and Medicaid funding for overnight respite;<sup>41</sup>
- discontinue the pilot and allow all adult day facilities to offer overnight respite provided they meet the current regulations for overnight respite at adult day care facilities and pay licensure fees; or
- discontinue the pilot and allow all adult day care facilities to offer overnight respite and collect state and Medicaid funding for overnight respite provided they meet the current regulations for overnight respite at adult day care facilities and pay licensure fees.<sup>42</sup>

Recommendation 2. The General Assembly should require state agencies and institutions initiating pilot projects at the direction of the General Assembly to adhere to standards established by the University of North Carolina at Chapel Hill's School of Government.

As discussed in Finding 2, the legislative mandate for the overnight respite pilot and its implementation by the Department of Health and Human Services only met two of the ten recommended components of a well-designed pilot program. As a result, the pilot program could not provide valid policy guidance on the provision of overnight respite in adult day care facilities.

To ensure that pilot programs or projects initiated by the General Assembly are properly designed to provide results, the General Assembly should require state agencies or institutions to utilize standards prepared by the School of Government when they are directed to complete a pilot project, field trial, or other temporary experiment.

The General Assembly should require the School of Government, in cooperation with other universities and researchers, to develop and publish the standards. The standards should provide a range of optional methods for accomplishing projects that would consider resources and time available. The initial standards should be finalized only after consultation with the Joint Legislative Program Evaluation Oversight Committee. The School of Government should be required to present the standards to the Chairs of the Joint Legislative Program Evaluation Oversight Committee

<sup>&</sup>lt;sup>41</sup> This alternative recommendation requires a State Plan Amendment approved by the U.S. Centers for Medicare and Medicaid Services.

<sup>&</sup>lt;sup>42</sup> This alternative recommendation requires a State Plan Amendment approved by the U.S. Centers for Medicare and Medicaid Services.

and to the Director of the Program Evaluation Division by July 1, 2015. If the joint committee does not hold a meeting within 90 days of receiving the submission of the standards, the consultation requirement should be considered satisfied. Thereafter, all pilot programs, field trials, or other temporary experiments initiated by the General Assembly would be required to adhere to these standards unless the General Assembly specifically exempts a pilot program from the requirement. The School of Government also should be authorized to update the standards as it deems necessary.

## **Appendices**

Appendix A: Legislation Authorizing Overnight Respite in Adult Day Care Facilities

Appendix B: Summary of State-Operated Overnight Respite Facilities

Appendix C: Methodology for Estimating Medicaid Costs for Reimbursing Overnight Respite in Adult Day Care Facilities

Appendix D: Alternative Recommendations

## **Agency Response**

A draft of this report was submitted to the Department of Health and Human Services for review. Its response follows the appendices.

# Program Evaluation Division Contact and Acknowledgments

For more information on this report, please contact the lead evaluator, Brent Lucas, at Brent.Lucas@ncleg.net.

Kiernan McGorty made key contributions to this report. John W. Turcotte is the director of the Program Evaluation Division.

## Appendix A: Legislation Authorizing Overnight Respite in Adult Day Care Facilities

## GENERAL ASSEMBLY OF NORTH CAROLINA SESSION 2011

### SESSION LAW 2011-104 SENATE BILL 512

AN ACT TO AUTHORIZE THE DEPARTMENT OF HEALTH AND HUMAN SERVICES TO PILOT AN OVERNIGHT RESPITE PROGRAM IN FACILITIES THAT OFFER ADULT DAY CARE.

Whereas, the population of adults who are elderly or disabled in North Carolina is expected to increase, thereby increasing the need for safe and available overnight respite care; and

Whereas, adult day care provides group care and supervision to adults who may be physically or mentally disabled; and

Whereas, adult day care provides care and supervision during the day, allowing caregivers a time of respite or allowing caregivers to attend to other duties, including work; and

Whereas, adult day care allows individuals to remain in their communities and/or in familiar surroundings, thereby prolonging or eliminating the need for placement in a long-term care facility; Now, therefore,

The General Assembly of North Carolina enacts:

**SECTION 1.(a)** Notwithstanding G.S. 131D-6(b), the Department of Health and Human Services shall conduct a pilot program to assess the provision of overnight respite services in adult day care programs. The Secretary shall select a minimum of two, and a maximum of four, stable and successful certified adult day care programs in which to conduct the pilot. At least two of the programs selected shall be operated by an organization that has been offering adult day care in North Carolina since 1980 and has received national recognition including all of the following criteria: designated as a National Model Adult Day Care Center by the Robert Wood Johnson Foundation, designated as the only Teaching Day Center for recipients of North Carolina adult day care startup funds, received the North Carolina Non-Profit Center's Non-Profit Sector Stewardship Award for exemplary stewardship of resources, and received Leadership in Energy and Environmental Design (LEED) certification.

**SECTION 1.(b)** The provision of 24-hour care under this act shall not exceed 14 consecutive calendar days, or more than 60 total calendar days, during a 365-day period, for each participant receiving overnight respite services. The capacity of the 24-hour overnight respite program authorized under this act shall not exceed six beds. The State is not authorized to pay for any overnight respite services offered through this pilot, and the pilot shall not be eligible to enroll or otherwise participate in the Medicaid program.

**SECTION 1.(c)** An adult day care program participating in this pilot shall be currently certified by the Department to provide adult day care. An adult day care program participating in the pilot shall be exempt from adult care home licensure pursuant to Article 1 of Chapter 131D of the General Statutes and shall be exempt from licensure under Chapter 131E and Chapter 122C of the General Statutes. The Department of Health and Human Services shall adopt rules to include minimum requirements to ensure the health and safety of adult day care overnight respite participants. These requirements shall specify program management, staffing, building specifications, fire safety, sanitation, nutrition, enrollment,

## Appendix A: Legislation Authorizing Overnight Respite in Adult Day Care Facilities (Continued)

medication management, and program activities. Participant assessments conducted by the adult day care pilot programs shall provide sufficient information to ensure appropriate care and to protect the health and safety of participants but shall not be more onerous than current adult day care assessments. The Division of Health Service Regulation shall have the authority to enforce the rules adopted by the Department. Prior to the provision of overnight respite services, an adult day care program participating in the pilot shall receive an initial inspection by the Division of Health Service Regulation for compliance with the rules. On a basis not less than every six months, the Division of Health Service Regulation shall conduct monitoring visits and shall also be responsible for the investigation of complaints. Each adult day care program participating in the pilot shall periodically report the number of individuals served and the average daily census to the Division of Health Service Regulation, on a schedule determined by the Division. The Division of Health Service Regulation shall have the authority to suspend admissions or terminate the pilot program at any time due to noncompliance with regulatory requirements which has resulted in death or serious physical harm, or when there is a substantial risk that death or serious physical harm will occur.

**SECTION 2.** The Department of Health and Human Services shall report on the status of the pilot once a year to the Program Evaluation Division. The Program Evaluation Division shall evaluate the provision of overnight respite services in an adult day care program through the experiences of this pilot. The evaluation shall include whether this pilot was successful as measured by the participants in receipt of overnight respite, the primary caregivers of participants, the adult day care programs participating in the pilot, and the Department of Health and Human Services. On or before October 1, 2014, the Program Evaluation Division shall provide a report to the General Assembly on the feasibility of continuing to provide overnight respite in an adult day care program.

**SECTION 3.** This act becomes effective when it becomes law; adult day care programs participating in the pilot shall be selected and have received an initial inspection by January 1, 2012; and this act is repealed June 1, 2015.

In the General Assembly read three times and ratified this the 26th day of May, 2011.

s/ Walter H. Dalton
President of the Senate

s/ Thom Tillis Speaker of the House of Representatives

s/ Beverly E. Perdue Governor

Approved 9:10 a.m. this 2<sup>nd</sup> day of June, 2011

## Appendix B: Summary of State-Operated Overnight Respite Facilities

During the course of this evaluation, the Program Evaluation Division learned the State operates four facilities that offer temporary overnight respite: the Greenwood Inn (the only facility with beds designated for overnight respite), Caswell Developmental Center, Murdoch Developmental Center, and Riddle Developmental Center (see table below). Each of these facilities charges clients a fee for overnight services.

The Greenwood Inn only accepts private-pay clients. The Greenwood Inn is charging more than 25 times less than CarePartners, a nearby adult day care facility that participated in the pilot. The Greenwood Inn charges \$8 a day for overnight respite, which includes both day and overnight services, compared to CarePartners's rate of \$150 a night (which does not include their average day service rate of \$55.75). In Fiscal Year 2013–14, the State spent \$48,039 on providing overnight respite to 139 clients at the Greenwood Inn. Had the facility charged CarePartners's total rate for a full day of respite (nightly rate of \$150 and its average rate for day services of \$55.75), the State would have received \$137,634 in the same fiscal year for the provision of a full day's care for those 139 clients in addition to the actual receipts generated by the program (\$5,568).

Caswell Developmental Center also operates temporary overnight respite when beds are available, accepts private-pay clients, and charges \$8 a day for overnight respite. In Fiscal Year 2013–14, the State spent \$47,187 for providing 86 days of overnight respite at Caswell Developmental Center. If the facility had charged the rates established by CarePartners, the State would have received \$17,007 in addition to the actual receipts generated by the program (\$688). Together, the State could have received \$154,641 from the Greenwood Inn and Caswell Developmental Center in addition to the actual receipts generated by the two programs (\$6,256).

The three developmental centers receive clients referred by their respective local management entities/managed care organizations, which can pay for the service using Medicaid waiver funds. Medicaid's North Carolina Innovations (formerly CAP-MR/DD) expended \$62,093 for 17 participants at the State's developmental centers. For two of the state facilities, Medicaid is paying a higher rate than the pilot facilities are charging. Murdoch Developmental Center is charging \$222.96 per night (which includes day services) and Riddle Developmental Center is charging \$494.36 per night (which includes day services), whereas the pilot facilities charge an average cost of \$150 a night (which does not include day services). Thus, Medicaid may be spending more on overnight respite at state-run developmental centers than it could spend on the same service if it were provided at adult day care facilities. A

The General Assembly may consider requiring the Division of State-Operated Health Care Facilities to reevaluate the rates the state facilities are charging to make them more comparable with the overnight rates charged by the pilot adult day care facilities. Division officials acknowledged the rate disparity during interviews with Program Evaluation Division staff and stated they would examine them.

<sup>&</sup>lt;sup>43</sup> North Carolina Innovations's expenditures are from November 1, 2010, to October 31, 2011.

<sup>&</sup>lt;sup>44</sup> This conclusion assumes the acuity of clients utilizing these facilities does not exceed the level of care provided by adult day health care facilities that provide overnight respite.

Appendix B: Summary of State-Operated Overnight Respite Facilities (Continued)

State Facility	Number of Beds	Rate (per day)	FY 2014 Number of Client Nights	FY 2014 State Cost of Offering Service
Greenwood Inn	6	\$8	696	\$48,039
Caswell Developmental Center				
Private Pay	-	\$8	86	\$47,187
Diagnostic/Therapeutic Respite	-	\$113	213	\$10 <i>4,</i> 749
Murdoch Developmental Center	-	\$223	15	\$8,390
Riddle Developmental Center	-	\$494	24	\$12,753
Total		-	1,034	\$221,119

Notes: Respite provided to individuals at the state-operated developmental centers (Caswell, Murdoch, and Riddle) is billed to the family/guardian as private pay or to the individual's managed care organization (MCO) if the individual is an North Carolina Innovations waiver recipient. Division of State-Operated Health Care Facilities staff explained the rates at the developmental centers vary because MCOs have the authority to set rates for waiver services. The Diagnostic/Therapeutic Respite provided at Caswell Center is an intensive service that includes assessments, evaluations, medication adjustments, and behavioral recommendations based on the unique needs of the individual, and Division of State-Operated Health Care Facilities staff stated this service differs greatly from the overnight respite services provided by the pilot adult day care facilities.

Source: Program Evaluation Division based on data from the Division of State-Operated Health Care Facilities.

# Appendix C: Methodology for Estimating Medicaid Costs for Reimbursing Overnight Respite in Adult Day Care Facilities

The Program Evaluation Division estimated the annual cost to the State for authorizing overnight respite at the four pilot facilities and at all 100 adult day care facilities based on two sources of data: actual data available from CarePartners and statewide estimates from a variety of sources.

Measure	Actual Data from CarePartners		Statewide Estimates from a Variety of Sources	
	Estimate	Explanation	Estimate	Explanation
Number of day clients (FY14)	1 <i>7</i> 1	Actual number of day clients	4,827	Actual number of DAAS-certified adult day care client slots
Percent of day clients that would use overnight respite	19%	Actual number of overnight clients in FY14 (33)/Actual number of day clients (171)	17%	Non-pilot facility estimate of percent of day clients that would use overnight respite
Number of overnight respite clients (FY14)	33	Actual number of overnight clients 821		Number of day clients (4,827) x non-pilot facility estimate of percent of clients who would use overnight respite (17%)
Percent of day clients eligible for Medicaid	4%	Actual number of Medicaid-eligible clients (6)/Actual number of day clients (171)	8%	Actual number of CAP-DA clients in adult day health care facilities (384) in FY12/Actual number of DAAS-certified adult day care client slots (4,827)
Number of days of overnight respite per client per year	32	(Number of days of overnight respite [173]/Number of overnight respite clients [33]) x Average number of stays (6)	20	Non-pilot facility estimate of stays (5) x Non-pilot facility estimate of days per stay (4)
Medicaid reimbursement rate (to be established by DMA)	\$150	Actual nightly rate	\$150	Median of actual nightly rate of four pilot facilities
Number of day clients eligible for Medicaid	7	Percent of day clients eligible for Medicaid (4%) x Actual number of day clients (171)	386	Percent of day clients eligible for Medicaid (8%) x Actual number of DAAS-certified adult day care client slots (4,827)
Number of Medicaid- eligible clients that would use overnight respite	1	Actual number of Medicaid-eligible day clients (7) x Percent of day clients that would use overnight respite (19%)	66	Number of day clients eligible for Medicaid (386) x Percent of day clients that would use overnight respite (17%)
Total number of nights Medicaid-eligible clients would use overnight respite	32	Number of Medicaid-eligible clients that would use overnight respite (1) x Number of days of overnight respite per client per year (32)	1,320	Number of Medicaid-eligible clients that would use overnight respite (66) x Number of days of overnight respite per client per year (20)
Total Medicaid cost for overnight respite	\$4,800	Total number of nights Medicaid- eligible clients would use overnight respite (32) x Medicaid reimbursement rate (\$150)	\$198,000	Total number of nights Medicaid- eligible clients would use overnight respite (1,320) x Medicaid reimbursement rate (\$150)
State's share of Medicaid costs (35%)	\$1,680	Total Medicaid cost for overnight respite (\$4,800) x State's share of Medicaid costs (35%)	\$69,300	Total Medicaid cost for overnight respite (\$198,000) x State's share of Medicaid costs (35%)

Source: Program Evaluation Division based on data provided by CarePartners and a survey of non-pilot adult day care facilities.

## Appendix C: Methodology for Estimating Medicaid Costs for Reimbursing Overnight Respite in Adult Day Care Facilities (Continued)

Using two separate sets of data produces an estimated range of the State's share of Medicaid costs for reimbursing overnight respite at adult day care facilities. Statewide data from a variety of sources produces the low end of the range for the State's annual share of Medicaid costs: \$693 for one facility, \$2,772 for the four pilot facilities, and \$69,300 for all 100 adult day care facilities. CarePartners data produces the high end of the range for the State's annual share of Medicaid costs: \$1,680 for one facility, \$6,720 for the four pilot facilities, and \$168,000 for all 100 adult day care facilities.

Measure	Statewide	Estimates from a Variety of Sources	Actual Data from CarePartners		
Measure	Estimate	Explanation	Estimate	Explanation	
State's share of Medicaid costs (35%) for one adult day care facility	\$ 693	State's share of Medicaid costs for 100 adult day care facilities (\$69,300)/Statewide number of adult day care facilities (100)	\$ 1,680	Total Medicaid cost for overnight respite (\$4,800) x State's share of Medicaid costs (35%)	
State's share of Medicaid costs (35%) for four pilot adult day care facilities	\$ 2,772	State's share of Medicaid costs for one facility (\$693) x Number of pilot adult day care facilities (4)	\$ 6,720	State's share of Medicaid costs for one facility (\$1,680) x Number of pilot adult day care facilities (4)	
State's share of Medicaid costs (35%) for 100 adult day care facilities	\$ 69,300	Total Medicaid cost for overnight respite (\$198,000) x State's share of Medicaid costs (35%)	\$ 168,000	State's share of Medicaid costs for one facility (\$1,680) x Statewide number of adult day care facilities (100)	

Source: Program Evaluation Division based on data provided by CarePartners and a survey of non-pilot adult day care facilities.

## Appendix D: Alternative Recommendations

The Program Evaluation Division recommends letting the pilot expire as set out by its establishing legislation. Other options regarding the provision of overnight respite in adult day care facilities were considered during this evaluation. These options are described below, with the benefits and challenges of each option summarized in the following table.

Alternative Recommendation	Potential Benefits of Recommendation	Potential Challenges of Recommendation	
Alternative Recommendation 1a.  Extend the pilot and allow the current pilot facilities to collect state and Medicaid funding for overnight respite	<ul> <li>Limits the number of adult day care facilities eligible to provide overnight respite</li> </ul>	<ul> <li>Increases state Medicaid expenditures by an estimated \$2,772 to \$6,720 annually (see Appendix C)</li> <li>Increases the demand on the Division of Medical Assistance in offering a</li> </ul>	
	<ul> <li>Continues to offer an overnight respite option for caregivers at pilot sites</li> </ul>		
	<ul> <li>Assists caregivers with the cost of obtaining overnight respite at pilot sites</li> </ul>	<ul><li>new service</li><li>Continues the demand on the Division</li></ul>	
	<ul> <li>Increases the likelihood caregivers will use the service at pilot sites because of financial assistance option</li> </ul>	of Health Service Regulation to inspect and monitor the four pilot facilities providing overnight respite	
	<ul> <li>Allows for re-evaluation of pilot success with more valid and consistent data before making a decision to cease or expand the service</li> </ul>	Requires later legislative action to determine if the service should be authorized statewide	
	<ul> <li>May reduce Medicaid costs if receiving overnight respite services at adult day care facilities delays institutional placement of Medicaid-eligible individuals</li> </ul>		
Alternative Recommendation 1b.  Discontinue the pilot and allow all adult day care facilities to offer overnight respite provided they meet the current regulations and pay licensure fees	<ul> <li>Expands the number of adult day care facilities eligible to provide overnight respite</li> </ul>	Number of adult day care facilities that would begin offering the service is unclear	
	<ul> <li>Provides an overnight respite option for caregivers</li> </ul>	Unclear whether Elderhaus will resume or Life Enrichment will begin offering service	
	<ul> <li>Reimburses the State for inspection costs</li> <li>May reduce Medicaid costs if receiving overnight respite services at adult day care facilities delays institutional placement of Medicaid-eligible individuals</li> </ul>	Increases the demand on the Division of Health Service Regulation to inspect and monitor adult day care facilities providing overnight respite	
Alternative Recommendation 1c.  Discontinue the pilot and allow all adult day care facilities to offer overnight respite and collect state and Medicaid funding for overnight respite provided they meet the current regulations and pay licensure fees	<ul> <li>Expands the number of adult day care facilities eligible to provide overnight respite</li> </ul>	Number of adult day care facilities that would begin offering the service is unclear	
	Provides an overnight respite option for caregivers	<ul> <li>Increases state Medicaid expenditures by an estimated \$69,300 to \$168,000 annually (see Appendix C)</li> </ul>	
	<ul> <li>Assists caregivers with the cost of obtaining overnight respite</li> <li>Increases the likelihood caregivers will use</li> </ul>	<ul> <li>Increases the demand on the Division of Medical Assistance in offering a</li> </ul>	
	the service because of financial assistance option	new service     Increases the demand on the Division	
	Reimburses the State for inspection costs	of Health Service Regulation to regulate and monitor adult day care	
	<ul> <li>May reduce Medicaid costs if receiving overnight respite services at adult day care facilities delays institutional placement of Medicaid-eligible individuals</li> </ul>	facilities providing overnight respite	

Source: Program Evaluation Division.

## Appendix D: Alternative Recommendations (Continued)

Alternative Recommendation 1a. The General Assembly should extend the pilot and allow the current pilot facilities to collect state and Medicaid funding for overnight respite. As discussed in Finding 3, the legislative prohibition against using state or Medicaid funding for overnight respite in adult day care hindered the effectiveness of the pilot. This alternative recommendation would maintain the current number of adult day care facilities participating in the pilot but would remove the legislative funding prohibition on the overnight respite service in an effort to collect more data to determine the need for overnight respite in adult day care facilities. This alternative recommendation would require a reevaluation in four years of the success of the pilot. The Program Evaluation Division estimates this alternative recommendation would increase the State's share of Medicaid costs by an estimated \$2,772 to \$6,720 for each remaining year of the pilot extension (See Appendix C).<sup>45</sup>

## If the General Assembly chooses this alternative recommendation, the following actions should be taken:

- Amend Session Law 2011-104 to move the pilot termination date from June 1, 2015, to June 1, 2019;
- Amend Session Law 2011-104 to remove the prohibition on the use of state and Medicaid funding;
- Require the Division of Medical Assistance at the Department of Health and Human Services to coordinate
  with the U.S. Centers for Medicare and Medicaid Services to establish a new service code for overnight
  respite and develop a flat reimbursement rate for overnight respite at adult day care facilities;<sup>46</sup>
- Require the Division of Aging and Adult Services at the Department of Health and Human Services to
  establish a new service code for overnight respite and develop a flat reimbursement rate for overnight
  respite in adult day care facilities through the Home and Community Care Block Grant and the Family
  Caregiver Support Program;
- Require the Division of Health Service Regulation to fully implement the recommended components of a well-designed pilot program as discussed in Finding 2:
  - o a conceptual framework demonstrating how the pilot program addresses the identified problem;
  - o fiscal analysis estimating the State's cost for a full-scale program;
  - o standardized performance criteria assessing the program's success, including but not limited to participant and caregiver satisfaction, effects of overnight respite on caregivers' personal and professional lives, percentage of day clients that used overnight respite, percentage of clients that used overnight respite more than once, and average monthly bed utilization;
  - a study design allowing for meaningful evaluation that limits threats to validity, including at a minimum designating four control group adult day care facilities that match the pilot group along an array of characteristics (e.g., urban vs. rural, percentage of clients that are Medicaid eligible) to determine the effects of overnight respite on caregivers' personal and professional lives;<sup>47</sup> and

<sup>45</sup> This alternative recommendation should not increase the cost of the Home and Community Care Block Grant and the Family Caregiver Support Program because clients have a maximum budget they can spend on approved services, one of which would now be overnight respite in adult day care facilities.

<sup>&</sup>lt;sup>46</sup> The Division of Medical Assistance does not anticipate the U.S. Centers for Medicare and Medicaid Services will have a statewideness issue with only four adult day care facilities receiving Medicaid funds for overnight respite.

<sup>&</sup>lt;sup>47</sup> The Program Evaluation Division did not recommend the Division of Health Service Regulation fully implement examination of whether alternative solutions could produce similar outcomes because a formal needs assessment to establish demand for overnight respite in adult day care facilities versus other settings would require substantial time and resources, which would only be warranted after the extended pilot is completed.

Require the Division of Health Service Regulation to report on the success of the pilot no later than October
 1, 2018, to the House Appropriations Subcommittee on Health and Human Services, Senate Appropriations on Health and Human Services Committee, Fiscal Research Division, and Program Evaluation Division.

Alternative Recommendation 1b. The General Assembly should discontinue the pilot and allow all adult day care facilities to offer overnight respite provided they meet the current regulations and pay licensure fees. As discussed in Findings 1 and 4, stakeholders view the pilot as successful and have anecdotal evidence of the need for overnight respite in adult day care facilities. This alternative recommendation ends the pilot and creates a new service available for any adult day care facility to provide.

#### If the General Assembly chooses this alternative recommendation, the following actions should be taken:

- Make the overnight respite program established in Session Law 2011-104 permanent by codifying the sections relating to restrictions on the service and the Division of Health Service Regulation's responsibilities; and
- Establish a licensure fee based on the rates set by N.C. Gen. Stat. § 131-267 and § 131E-272 for other facilities providing overnight respite (see table below).

	Construction Review Fee	Initial License Fee	Renewal Fee
Family care home	\$225 flat fee	\$350 flat fee	\$315 flat fee
Adult care home	\$275 flat fee	\$400 plus \$19 per bed	\$360 plus \$17.50 per bed
Nursing home	\$275 flat fee	\$470 plus \$19 per bed	\$420 plus \$17.50 per bed

Note: The \$275 flat fee for construction review of adult care homes and nursing homes is for facilities with 7 to 9 beds; when these two types of facilities have more than 9 beds, they are charged \$275 plus \$0.15 per square foot.

Alternative Recommendation 1c. The General Assembly should discontinue the pilot and allow all adult day care facilities to offer overnight respite care and collect state and Medicaid funding for overnight respite provided they meet the current regulations and pay licensure fees. As discussed in Findings 1 and 4, stakeholders view the pilot as successful and have anecdotal evidence of the need for overnight respite in adult day care facilities. Further, Finding 3 suggests facilities will be more likely to provide and caregivers will be more likely to utilize the service if the legislative prohibition against using state and Medicaid funding for the service were removed. This option ends the pilot, creates a new service available for any adult day care facility to provide, and allows these facilities to collect state and Medicaid funds for providing overnight respite. The Program Evaluation Division estimates this option will increase the State's annual share of Medicaid costs between \$69,300 and \$168,000 (see Appendix C).<sup>48</sup>

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<sup>&</sup>lt;sup>48</sup> This option should not increase the cost of the Home and Community Care Block Grant and the Family Caregiver Support Program because clients have a maximum budget they can spend on approved services, one of which would now be overnight respite in adult day care facilities.

#### If the General Assembly chooses this alternative recommendation, the following actions should be taken:

 Make the overnight respite program established in Session Law 2011-104 permanent by codifying the sections relating to the establishment of the service and the Division of Health Service Regulation's responsibilities and by removing the prohibition on the use of state and Medicaid funding;

- Establish a licensure fee based on the rates set by N.C. Gen. Stat. § 131-267 and § 131E-272 for other facilities providing overnight respite;
- Require the Division of Medical Assistance at the Department of Health and Human Services to coordinate
  with the U.S. Centers for Medicare and Medicaid Services to establish a new service code for overnight
  respite and develop a flat reimbursement rate for overnight respite at adult day care facilities; and
- Require the Division of Aging and Adult Services at the Department of Health and Human Services to
  establish a new service code for overnight respite and develop a flat reimbursement rate for overnight
  respite in adult day care facilities through the Home and Community Care Block Grant and the Family
  Caregiver Support Program.



## North Carolina Department of Health and Human Services Division of Health Service Regulation

Pat McCrory Governor Aldona Z. Wos, M.D. Ambassador (Ret.) Secretary DHHS

> Drexdal Pratt Division Director

September 29, 2014

John W. Turcotte Program Evaluation Division, North Carolina General Assembly Legislative Office Building, Suite 100 300 N. Salisbury Street Raleigh, NC 27603

Dear Mr. Turcotte:

The Department of Health and Human Services has reviewed the Program Evaluation draft report 2014-11, and is thankful for your Division's evaluation of the success of the pilot program authorized by Session Law 2011-104 to provide overnight respite at adult day care facilities in North Carolina. Please accept this letter as the formal response to the draft report.

Ensuring the health, safety, and well-being of all North Carolinians is the top priority for the Department. For the successful implementation of this pilot program, the legislation directed DHHS to adopt rules to include minimum requirements to ensure the health and safety of adult day care overnight respite participants. The Department's Division of Health Service Regulation was given the authority to enforce the rules adopted by the Department, to conduct monitoring visits, and was responsible for the investigation of complaints.

Additionally, the Department's Division of Aging and Adult Services played an integral role in conducting this pilot as it is responsible for planning, administering, coordinating, and evaluating the activities developed under the Older Americans Act and programs for older adults, as funded by the General Assembly. This Division is responsible for certifying adult day care facilities throughout the state.

The first recommendation of Program Evaluation's draft report is for the General Assembly to allow the pilot program authorizing overnight respite services in adult day care facilities to expire on June 1, 2015. The Department is in agreement with this recommendation. However, the Department does not endorse nor has it validated the methodology used by the Program Evaluation Division in Appendix C on page 44, Methodology for Estimating Medicaid Costs for Reimbursing Overnight Respite in Adult Day Care Facilities.

The Department disagrees with the Program Evaluation Division's finding that it only met two of the ten recommended components of a well-designed pilot program and its corresponding second recommendation. Session Law 2011-104 provided very specific direction to the Department with regard to its administration of the program. The Department adhered to these directions. The Session Law does not reference the 2008 Fiscal Brief cited by the Program Evaluation Division as authority for these findings and recommendations nor was the Department otherwise obligated to adhere to it.

The Department of Health and Human Services is grateful to the Program Evaluation Division of the General Assembly for its professionalism and proficiency throughout the entirety of this process.

Sincerely.

Office of the Director

http://www.ncdhhs.gov/dhsr/ Phone: 919-855-3750 / Fax: 919-733-2757

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# Program Evaluation Division Response to the Department of Health and Human Services Response

## Finding 2 and Recommendation 2

**DHHS Response:** The Department disagrees with the Program Evaluation Division's finding that it only met two of the ten recommended components of a well-designed pilot program and its corresponding second recommendation. Session Law 2011-104 provided very specific direction to the Department with regard to its administration of the program. The Department adhered to these directions. The Session Law does not reference the 2008 Fiscal Brief cited by the Program Evaluation Division as authority for these findings and recommendations nor was the Department otherwise obligated to adhere to it.

## **Program Evaluation Division Response**

The Program Evaluation Division used the criteria for a well-designed pilot project proposed by the 2008 Fiscal Brief as a systematic tool to evaluate the Department of Health and Human Services' implementation of the overnight respite pilot. Nothing in the legislation authorizing the pilot precluded the department from implementing a well-designed study allowing for meaningful evaluation. At a minimum, the department could have collected information on the number of clients that received the service and utilization of the service, or satisfaction information. Pilot sites stated that they would collect this information in their initial application, but DHHS did not request or require them to provide it.

#### Appendix C

**DHHS Response:** The first recommendation of Program Evaluation's draft report is for the General Assembly to allow the pilot program authorizing overnight respite services in adult day care facilities to expire on June 1, 2015. The Department is in agreement with this recommendation. However, the Department does not endorse nor has it validated the methodology used by the Program Evaluation Division in Appendix C on page 44, Methodology for Estimating Medicaid Costs for Reimbursing Overnight Respite in Adult Day Care Facilities.

### **Program Evaluation Division Response**

As is standard procedure for all Program Evaluation Division reports, the Department of Health and Human Services was provided a preliminary draft of the report on August 27, 2014. The preliminary draft included the Program Evaluation Division's estimates of Medicaid costs for reimbursing overnight respite in adult day care facilities. The Department of Health and Human Services chose not to review these estimates, even after the Program Evaluation Division gave the department two extensions by which to do so. As of September 29, 2014, the department had still not reviewed the methodology. Because the legislation mandating the study had a due date of October 1, 2014, the Program Evaluation Division decided to release the report without the department's validation of the Medicaid estimates.