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Adult Day Services: Sharing the Caring, Having a Life

The scenario is repeated many times every morning across Virginia. Older Virginians, many in their 80s and 90s, get up and dressed, leave home, and go off to spend an active day with friends. For these older adults with Alzheimer's disease, post-stroke disabilities, Parkinson's disease, or dozens of combinations of other diagnoses, 'going to the center' has become the focal point of their daily routines. The center is their primary source of daily nursing, personal care, and restorative services, and of their sense of purpose, connection, and community. Most of these older adults are at imminent risk of needing residential care, yet live at home, usually with family caregivers who work or are older adults themselves. Adult day services make living at home possible.

Adult day services 'share the caring' with family members who can provide some, but not all, of their parent's or spouse's care. This service, which merges the economies and reliability of congregate care, the often preferred opportunity to continue living at home, and a multidisciplinary team approach, makes sense as a long-term care option. Provided primarily by non-profit and public agencies, adult day services grew out of the grassroots needs of Virginia's families and communities. Growing from a few urban centers in the mid-1970s, programs have now spread to smaller cities and towns like Winchester, Smithfield, Blackstone, Farmville, and St. Paul.

Psychosocial Benefits

Staff in the licensed centers across Virginia could write volumes about the impact of adult day services on the lives of the individual frail and impaired older adults they serve. Although most elders are initially reluctant to attend, the rich and varied milieu usually works its magic, adding meaning and purpose, a sense of place, and structure to lives that have narrowed due to limitations that come with age and disability. After a few days of adult day services, family members report changes

such as a renewed enthusiasm for life, better sleep after a busier day, and something to share with the family at dinner. Even those with mid- and later-stage dementia demonstrate positive changes: more smiles, hugs for staff, diminishing anxiety when family caregivers leave for the day, and increasing involvement in activities and routines.

Family caregivers report adult day services change their lives as well. Elderly spousal and sibling caregivers benefit from regular, reliable respite, 'having the house to themselves,' time for rest, self-care and their own health needs, help with physical caregiving, emotional support from staff, assistance with health care decisions and resources, and myriad other benefits. Working caregivers report fewer work interruptions and lost work days because of the reliability of center-based care, help from staff to learn caregiving skills, and time to resume other valued life roles such as friend, volunteer, and church member. All families find comfort in the safe center environment and the constant professional super-vision provided, both to the elders in care and center staff.

Health Services

Health services are an equally important element of adult day services, although centers vary in the range and scope of services provided. In Virginia, most provide daily, on-site nursing care by RNs and LPNs. At least two centers have nurse practitioners on staff in response to growing acuity levels and complexity of needs. Aide and assistant staff may be certified nursing assistants, certified adult day health care aides, or recreation assistants. In addition, most centers have therapeutic recreation specialists or degreed staff with arts, activity, or gerontology backgrounds. Some centers have staff with social work or counseling degrees, and several have occupational therapists or certified occupational therapy assistants. The centers in Virginia certified by Medicaid also provide rehab coordination. Many offer physical, occupational, and speech therapy at the center through Part B Medicare-certified home care agencies. Regardless of the health services provided, all licensed centers operate from individualized written care plans, based in the multidisciplinary assessment of each participant's needs.

Financing Care

Paying for adult day services is less problematic than most families and other agencies expect. Adult day services are an economical alternative for those who must pay out of pocket for long-term care. For those who itemize, adult day services are a qualified medical expense when filing federal tax returns. Medicaid pays for adult day health care and transportation, alone or in combination with in-home personal care, for those who meet financial and Uniform Assessment Instrument (UAI) nursing home criteria. Most public and non-profit centers also offer scholarships or sliding fee scales based on income. Many centers factor in reasonable household and medical expenses, so even middle-income families can qualify for discounted fees. Long-term care insurance policies also cover adult day services.

Utilization

There are several perceived barriers to the effective utilization of adult day services. Many families and potential referral sources do not understand the service or fail to consider this option when long-term care is needed. Others have heard that it is 'expensive' when, in reality, few are turned away if the cost is truly a barrier. Transportation may be a real or perceived barrier. Center staff can be particularly helpful in problem-solving transportation alternatives. The older person's reluctance to attend may present ethical dilemmas, but family caregivers can be reassured that encouragement to 'give it a try' almost always produces subsequent positive attitudes. Family caregivers may face their own ethical dilemmas about lost roles and empty daytime nests, but mature adult caregivers understand that older relatives have legitimate needs for 'a life' apart from family. Respite is a two-way street! Of course, some elders are truly home-bound, have very unstable health conditions, or present behaviors that cannot be resolved. Generally, centers cannot serve those who are combative, persistent wanderers, or those who are unable to attend with some regularity due to health or family issues.

Outcomes

Until recently, the impact of adult day services on individual lives has been recorded through rich, albeit anecdotal, stories of change over time. More objective evidence of positive program outcomes are emerging as centers develop methodologies to document other kinds of 'savings.' For example, Circle Center Adult Day Services (CCADS) has as a primary goal to delay or prevent nursing home placement,

allowing program participants to live at home as long as possible. The Center uses the UAI to assess all participants. For the population served July 1, 1999 - June 30, 2000, 88% met nursing home admission criteria. If instead, they had entered nursing homes, the Center prevented some 23,516 days of nursing home placement, a net saving for families and taxpayers of approximately \$1,374,446. Outcomes for family caregivers were also positive. In confidential surveys, caregivers reported use of Center support and educational resources (100%), said the Center helped them cope (96%), met their needs for help with caregiving (96%), and helped them maintain valued life roles such as worker, caregiver, church member, and volunteer (100%).

Case Study

Mrs. B. is 82, has Alzheimer's, depression, and hypertension, and is cared for by her 83-year-old husband. Mr. B. describes life before the center as a 'daily nightmare.' Mrs. B. paced, cried, and ruminated, unable to perform routine household and selfcare tasks after a lifetime of caring for their home and family. An energetic man with many skills and interests, Mr. B. was essentially housebound and felt helpless to resolve his wife's emotional pain and confusion. Their adult children encouraged him to try adult day services, if only for his own respite. After a few weeks, Mr. B. and center staff agreed there had been dramatic changes in Mr. and Mrs. B.'s lives. Mrs. B. remained confused, but came to the center with enthusiasm, calling it 'school,' enjoyed simple activities, the companionship of other participants, and the affection and support of staff. The center nurse practitioner and the family's physician identified a medication regimen that effectively controlled Mrs. B.'s residual depression, anxiety, and sleeplessness. As Mrs. B. was dangerously underweight due to depression and self-feed problems, the center's occupational therapist resolved issues related to positioning, equipment, and pacing of meals. Mrs. B. began to gain weight. Occasional urinary incontinence was prevented with a scheduled voiding program which Mr. B. continues during his wife's time at home. Mr. B. reports feeling more in control, knowing that his wife is receiving daily nursing care and monitoring. He regularly attends the center's MSW-led family support group with other men who are also caring for their wives. The B.'s adult children are elated and wrote touching letters to the center staff, thanking them for 'giving both of our parents their lives back.'

Finding Out More and Choosing an Adult Day Services Center

There are several resources to help you make a choice about Adult Day Services. The Virginia Department of Social Services (VDSS) rates these programs across the state on staff qualifications, patterns and ratios, facility management, emergency preparedness, and the program itself. The VDSS website has a <u>searchable database</u> for finding adult day care centers by name, locality, zip code.

The National Adult Day Services Association (NADSA) has created "Choosing a Center". This will help you in your search for quality, community Adult Day Services.

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