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Controversies in Care

COVID-19 and the Need for Adult Day Services

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A B S T R A C T

COVID-19 has shone a harsh light on the inequities of health care in the United States, particularly in how we care for older people. We summarize some of the effects of lockdown orders on clients, family caregivers, and staff of adult day service programs throughout the United States, which may serve as a counterpoint to scientific evidence suggesting a lack of efficacy of these programs. Given the ramifications of state lockdown orders for users and staff of the long-term services and support system, we provide recommendations to better support community-based programs and those they serve. Specifically, (1) adult day programs should be classified as essential, (2) a focus on the value of adult day and similar programs is needed, and (3) an exploration of new ways to finance home and community-based services is warranted. Such advances in policy and science would help to integrate adult day services more effectively into the broader health care landscape.

Older persons and care staff in nursing homes have faced appalling challenges because of COVID-19 (particularly those who are underserved and underrepresented). However, less public health or media attention has considered those who provide the majority of long-term care in the United States: family caregivers. Eighty-three percent of older Americans aged ≥70 years receive help from unpaid caregivers, most commonly their relatives.[1] If family caregivers were to suddenly stop providing help to older Americans in need, the long-term care system of the United States would effectively collapse.[2] Although the heavy reliance on family caregivers in the United States offsets the needs for costly long-term services and supports (such as residential long-term care), over 4 decades of scientific research has emphasized the significant and sometimes adverse health implications of caregiving, particularly on family caregivers of persons living with complex, chronic conditions such as Alzheimer's disease and related dementias.[3]

In order to manage their day-to-day care activities, many family caregivers rely on a patchwork of community services and supports that allow them to continue to provide care to relatives at home and, for many, to remain employed. Adult day programs provide services and social activity out of home to older persons with a range of health needs, often during daytime hours.[4] Adult day services are also able to offer respite and relief to family caregivers so they can work, run errands, or have time to recharge emotionally, psychologically, and physically. Staffed by nurses, social workers, health aides, activity professionals, and other health professionals such as occupational therapists, adult day programs serve a diverse, predominantly older clientele that is approximately one-third black,[5,6] indigenous, or of color.[7] Compared with other home- and community-based supports, adult day programs are among the most racially and ethnically diverse.[7,8] As of 2016, there were 4600 adult day programs serving approximately 286,300 older adults throughout the United States.[9]

This article grapples with a controversy of sorts: on one side the expressed need from family members, providers, and advocates of the necessity of adult day programs and their sense of loss when these services were closed during COVID-19, and on the other side the

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prevailing scientific evidence, which by and large has concluded these programs lack efficacy in randomized controlled evaluations (see Table 1).

Background of Adult Day Services

As adult day programs grew in popularity with the deinstitutionalization movement in the 1960s, various efforts attempted to determine and identify "types" of adult day programs in the United States. Work by Weissert and colleagues in the 1970s identified 2 predominant models of adult day services following a survey of 10 such programs in the United States: model I, or "medical," programs that provide skilled therapy and services to older clients, and model II, or "social," programs that emphasized social interactions, nutrition, and activities. In the 1980s Weissert and colleagues conducted the National Adult Day Care Survey, which included a larger, more systematic sample of 60 adult day programs. Three categories of programs were identified: Auspice Model I (which were focused on rehabilitation and were often affiliated with nursing homes or hospitals); Auspice Model II (offering case management, counseling, transportation, assessment, etc), and Special Purpose (programs that targeted clientele with specific needs). Other efforts dating from the 1980s[10,11] as well as more recent descriptive studies[12] have identified an even larger range of adult day program types, including programs with specific foci on dementia care, rehabilitation, and programs that vary widely based on the functional and health needs of their clientele.[13]

Funding for adult day services is complex and variable. Providers rely on a combination of public and private funding, grants, and donations to cover the cost of care. Medicaid is the payer source for the majority (66%) of adult day service participants, with the intent by states to divert dollars from more expensive nursing home care to adult day or other home- and community-based services for individuals of low income.[9] The Veterans Administration is the second largest public source of reimbursement. Medicare does not pay for adult day services. Some participants pay out of pocket for care (at an estimated cost of $70 per day) and even fewer use long-term care insurance to pay for care.[14,15]

Prior Research on the Efficacy and Effectiveness of Adult Day Services

Prior systematic reviews of the efficacy and cost-effectiveness of adult day services generally conclude that when subjected to randomized controlled evaluations, these programs do not reduce older persons' nursing home admission or other health care costs nor do they alleviate family caregiver distress. Most randomized controlled evaluations of adult day service programs were conducted from the late 1970s through the 1980s, and the lack of effect of these programs in early research demonstrations led to various recommendations including improved "targeting" of such services to those at the greatest risk of nursing home admission or other high needs.[15–20]

Research conducted on adult day services since the 1990s has raised concerns that the use of randomized controlled designs when evaluating adult day services may not capture how and why these programs may exert benefits for users. For example, challenges in creating tightly controlled treatment and comparison conditions, differential attrition across treatment and control groups, inadequate operationalization of the treatment under study, and lack of insight as to mechanisms of benefit have led to some criticism as to whether a randomized controlled trial strategy that overemphasizes internal validity is appropriate (ie, achieving internally valid control obscures the complex contexts within which adult day programs often operate).[21,22] More recent studies using various types of quasi-experimental designs and simulation models have suggested more promising effects of adult day programs on client and caregiver outcomes, but often are excluded from systematic reviews or meta analyses because of their nonrandomized designs.[16–18]

The Real-World Implications of Eliminating Adult Day Services as a Home and Community-Based Service Option

In some respects, the COVID-19 pandemic has created a tragic, natural experiment to consider the "controversy" as to whether these community-based service options are effective or not. For example, we are currently conducting a national study involving 57 adult day service programs funded by the National Institutes of Health (R01 AG049692). Referred to as the ADS Plus, we are evaluating whether training staff to provide dementia education, nonpharmacologic strategies, and care management support to family caregivers who use adult day programs results in improved outcomes for older clients with dementia and their caregivers.[19] We were in the midst of the trial when, in March 2020, states across the United States made the decision to shut down adult day services to contain the spread of SARS-CoV-2. Since then, we have heard firsthand an outpouring of anguish, grief, confusion, and anger from families whose relatives can no longer access programs as well as from staff and directors who are struggling to meet the needs of clients and family caregivers.

In August 2020, we reached out to 30 of the adult day programs active in our study to better understand the impact of the COVID-19 pandemic on their clients, family caregivers, and overall service delivery. Of the sites sent the survey, 22 (73.3%) responded. Almost all sites (95.5%, n=21) had to close their doors to clients and caregivers. Those that had to close were often forced to cut back on their workforce, with 15 sites (71.4%) furloughing all or some staff and 3 sites (14.3%) terminating all or some staff. If staff were retained, their hours were cut. Three (14.3%) sites, owned by large corporations, were able

Table 1
The "Controversy" of Adult Day Services and Their Effectiveness

Adult Day Programs Are Ineffective	Adult Day Programs Are Essential
Research • The lack of efficacy of adult day services in randomized controlled trials Practice/Policy • Adult day services are not essential programs, and closing them during COVID-19 lockdowns is appropriate	Research • More up-to-date research on the efficacy of ADS using randomized controlled trials is unlikely • There is a need to consider alternative research designs when evaluating adult day services • Adult day services should be considered from a different perspective: how they are valued by clients, caregivers and staff Practice/Policy • Scale up integrated models that have adult day services at their core such as Programs of All Inclusive Care for the Elderly (PACE) • Use policy to ensure more comprehensive financing for home and community-based services

ADS, adult day services.

to reassign staff to other parts of the corporation (ie long-term care, housekeeping, dietary services). Most sites (66.7%, n=14) were able to maintain at least some staff that could work from home, primarily nurses and social workers. When programs are able to reopen, 13 sites reported (61.9%) that staff are willing but reluctant to return to work due to COVID-19.

A family caregiver and essential worker shared how difficult it has been without adult day services: "I have cut back on the hours that I've worked, but I still have gone to work and I've just left her. She can be by herself, but I have to check in constantly. . . . I wish I was a nonessential worker and could stay home and be with my mother" (female caregiver, 55 years old). Another caregiver expressed how the closing of her relative's program has negatively impacted his own livelihood, his well-being, and his mother's well-being: "the [adult day] site closed right after the pandemic started. It has been almost 6 months now. It has affected me financially, as I mentioned earlier . . . it has affected me emotionally . . . I have had to go to therapy more often in order to deal with having to be between 4 walls with my mom. . . . My mom misses [the adult day program] a lot. She lets me know this, within her abilities and limitations of her disease" (male caregiver, 60 years old).

A director shared how their program is not able to currently meet the needs of family caregivers. "I think that's the biggest challenge for caregivers: that they're not able to get the same level of services they were before COVID." Similarly, another program staff member mentioned how limiting the number of staff has even resulted in placing participants on waiting lists to receive adult day services.

In addition to our national ADS Plus study, our team has collaborated on state-commissioned surveys of adult day programs. These surveys reveal similar challenges. For example, 65% of programs in Ohio reported laying off or reducing staff pay after 4 months of forced closure due to an Ohio Department of Health executive order. During this same period, 83% of program directors reported that participants had to move to higher and more expensive levels of care such as nursing homes and assisted living facilities.[20] One Ohio program director stated, "We believe this isolation has increased participant acuity and health issues. Participants are experiencing signs of worsening dementia." Another reported, "They (caregivers) are now caregiving alone; stress, anxiety and social isolation has increased significantly." Ohio adult day programs reported that 74% of caregivers had to choose between working and taking care of their family members. "We have heard from several (now full-time) family caregivers that their employers have given them until the beginning of August to return to work or they are at risk of losing their job." Ninety-one percent of adult day program directors in Ohio reported their caregivers were experiencing an increase in stress and anxiety.

On March 5, 2020, the State of Maryland issued an Executive Order to close adult day programs in order to control and prevent the spread of COVID-19 within the state.[21] Participant enrollment numbers have declined because of death, deteriorating health resulting in transfer to residential long-term care, and out-of-state moves. Because programs in Maryland have not been permitted to admit new participants since the start of the executive order, a majority of adult day centers in the state have had to lay off staff (75%) and/or reduce staff hours (86%). Many centers rely on Daily Care Connections administrative Medicaid funding, but 50% of the adult day centers surveyed in Maryland indicated that they will close immediately or in 1 month if funding ceases at the end of December 2020.[22]

It is important to note that because of the challenge and upheaval posed to adult day programs, collecting proximal data on clients and caregivers of these services across states is challenging. Nevertheless, the ADS Plus project has been collecting close-ended and open-ended data from participating programs to document the effects of the COVID-19 pandemic on the operation of adult day services throughout the United States (some of which is presented above), and perhaps as important, the strategies and approaches these programs adopted to remain functional during unprecedented lockdowns and funding disruptions.

Recommendations

Reconsider Adult Day Programs as Essential

COVID-19 has shone a harsh light on how the US health care system is fragmented along the lines of acute care (often delivered in hospitals) and chronic care (nursing homes and community providers), with the majority of resources going to the former. Reimbursement mechanisms should incentivize new and expand upon integrated models of acute and chronic disease care for older persons. Otherwise, we will continue to prioritize some types of health care services at the expense of others. Classifying adult day programs as essential services could provide older adults and their caregivers the support needed to delay or avoid higher costs for more intense health care services.

To address the question of *if* adult day centers could remain *open safely* during the pandemic, studies during the pandemic have found that the COVID-19 infection rate was lower among older adults who used home- and community-based services (HCBS) compared with those living in assisted living or nursing homes, although it is important to note HCBS as defined did not consider adult day services.[23] Perhaps the most logical comparison can be drawn from child care centers that, in some cases, remained open during the pandemic. Adult day services and child care centers tend to share some similarities, including physical layouts and services (eg, social programs, health promotion, nutrition). Federal bodies provided specific, detailed guidelines on child care center operations during the pandemic, including infection control procedures, social distancing strategies, food service protocols, and education and training mandates for staff and families.[24,25] Subsequent research on child care centers and youth day camps that remained open during the pandemic have revealed that the threat of transmission of COVID-19 was an "unlikely" threat to staff members and youth when proper precautions were taken.[26,27] Had adult day services been deemed essential, these same operating guidelines may have allowed programs to continue to serve older adults and their families safely and effectively.

It is unclear, and unlikely, that statewide classifications of certain types of health care services as "essential" are based solely, or even in part, on scientific evidence. Nonetheless, there may be some health services researchers who may tacitly or overtly concur that because they have not yielded efficacy in randomized controlled trials dating back to the late 1970s, adult day programs should indeed be considered nonessential. However, we would argue innovation has taken place since these earlier trials and has resulted in community-based integration of acute and chronic disease care under the programmatic umbrella of adult day services. One example is the Program of All-Inclusive Care of the Elderly (PACE), which includes the integration of funding and provider risks via capitated Medicare and Medicaid payments; the delivery of both acute and chronic disease care within an adult day program and community-based setting; and case management.[28,29] Programs of All-Inclusive Care for the Elderly serve older people 55 years of age and over who are certified as nursing home eligible by their state of residence and live at home. A PACE program can serve anywhere from fewer than 20 to thousands of clients, although there exist only 134 PACE programs throughout the United States. Although not without challenges related to staffing, recruitment and enrollment, client targeting, and specialty referrals that may lead to adverse events for frail older persons with comorbid conditions,[30] PACE is often upheld as a model program that integrates community-based and acute care services. Unlike adult day services or

other senior care programs, PACE enrollment has remained steady during COVID-19.[31] PACE programs' inherent flexibility in their use of capitated funds and the services they provide demonstrate the capabilities of this model even during the extreme challenges posed by a global pandemic such as COVID-19.[31]

In the context of the controversy of this article, it is important to note that no randomized controlled evaluation of PACE exists to our knowledge, but a range of descriptive and controlled analyses have found that PACE appears to exert positive effects on a number of health outcomes for clients (similar to the recent, non-RCT findings demonstrating the benefits of adult day services summarized earlier).[30,31] Although it would be incorrect to suggest PACE and adult day programs as interchangeable, PACE demonstrates that the community-based platform of adult day programs has considerable potential when integrated and/or coordinated with other services to achieve benefits for older persons and their caregivers. To this end, we recommend that greater attention to the scaling of PACE occurs so that it is (1) more widely available across all states and beyond the 134 sites that currently operate and (2) adult day programs continue to be utilized as platforms for service innovation (with the required funding streams) so that they can achieve their goals for which they were originally designed, rather than classify these programs as nonessential.

Focus on the Value of Adult Day Services

Related to the recommendation above, we believe that the issue of whether adult day programs or other HCBS are efficacious or not via randomized controlled designs has likely passed. Significant policy efforts to "rebalance" state expenditures away from costly residential long-term care and toward HCBS have occurred over the past 2 decades, with the ostensible goal of assisting older persons remain at home for longer periods of time and preventing more costly transitions to residential long-term care. Given the lack of evidence of HCBS to delay nursing home admission or, in general, to reduce care expenditures for older persons, why should such efforts occur or receive support from health services/long-term care researchers? One reason is that older persons and family caregivers prefer such services at home; the growth in adult day services over the past 4 decades along with other HCBS is a testament to this preference. Another reason is the need for greater emphasis on the value of HCBS to older clients and their family caregivers and less on whether such programs achieve overall cost savings.[23,29,30,32,33] A third reason, and one tragically demonstrated during COVID-19 as well as prior incidents of multidrug-resistant outbreaks, is the high risk of infection transmission and dissemination in residential care settings.[34–36]

Such issues are particularly resonant for people of color, who due to cultural values regarding care often prefer treatment at home compared with residential institutions.[37] As indicated earlier, adult day services are the most racially diverse HCBS.[7] Utilization of adult day services is likely linked to the cultural preferences of such groups to receive care at home. This is a crucial consideration, as historical discriminatory practices while seeking health services endured by racial and ethnic groups in the United States has been cited as a factor to their underutilization of supportive services.[38] Without adult day services, racial and ethnic groups may be forced to rely on out-of-home services (ie institutionalization) for care, which may be costly and not aligned with their cultural preferences.

Changes in federal law to allow for greater flexibility in Medicaid spending for HCBS would not only provide caregivers and clients with more options; it would decrease the dependence on residential long-term care as the only care option afforded to some older people. In response to the deadly COVID-19 crisis in long-term care, calls to restructure, or "disrupt," the financing of long-term services and support in favor of funding more HCBS have begun.[39,40]

Refinancing HCBS

There may be opportunities to capitalize on temporary funding and programming exceptions that have been developed during the pandemic, or in "making lemons from a very sour lemon."[41] Funding for the delivery of adult day services via telehealth has been approved in several states and may represent an opportunity for permanently expanding this option following the resolution of COVID-19.[42]

There are other innovative financing alternatives to consider such as public-private long-term care insurance partnerships. Because of the inability or unwillingness of many Americans to save for long-term care in later life as well as the difficulty in predicting the amount of long-term care required, expanded insurance strategies where the lower front-end costs of long-term care are assumed by private insurance and the "catastrophic" later long-term costs such as residential services are assumed by public insurance programs could potentially improve financing for HCBS.[43,44] In addition, the state of Washington has taken a bold policy step to provide its residents with an account to purchase community-based long-term care services such as adult day programs. Signed into law in 2019 (HB 1087 and SB 5331), the Washington Long-Term Services and Supports Trust Act (or Trust for short) is financed through a payroll tax mechanism. The Trust is designed to provide up to a $36,000 benefit to spend toward long-term services and supports during state residents' first year of eligibility, and the benefit is anticipated to increase over time.[45] In addition to prior employment criteria, beneficiaries must require help with at least 3 activities of daily living. Following a robust grassroots effort on the part of advocates and organizations to lobby legislators, voter support across age brackets in Washington was achieved with 61% of voters and 55% those aged $\geq$65 years supporting the Trust and its payroll tax financing mechanism.[45]

President Biden's "Mobilizing American Talent and Heart to Create a 21st Century Caregiving and Education Workforce" proposes to provide federal funds ($775 billion over 10 years) to states as well as tribal and local state governments to support the direct care workforce and to "expand access to a broad array of" HCBS via Medicaid to innovate community-based care service delivery (this would include dissemination and implementation of evidence-based support programs).[46] Tax and Social Security credits for family caregivers and elimination of waitlists for HCBS are other key elements of President Biden's family caregiving policy proposal.[47] Elements of President Biden's campaign proposal have been incorporated in the 2021 infrastructure bill. Whether such proposals will result in actual policy advances or support expansion of and access to HCBS remains to be seen (particularly for the large number of older adults and families who are not Medicaid eligible).

The COVID-19 pandemic has not only highlighted ongoing and exacerbating gaps in how residential long-term care is regulated, financed, and delivered but also how HCBS such as adult day programs for families, friends, and others who provide at-home, intensive assistance to older Americans in need are essential. Instead of shutting down adult day services, we should be integrating these necessary programs into the broader health care system landscape.

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