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## Advance directives state requirements, center practices, and participant prevalence in adult day services centers: Findings from the 2016 National Study of Long-Term Care Providers

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### Abstract

**Objectives:** Adult day service centers (ADSCs) may serve as an entrée to advance care planning. This study examined state requirements for ADSCs to provide advance directives (AD) information to ADSC participants, ADSCs' awareness of requirements, ADSCs' practice of providing AD information, and their associations with the percentage of participants with ADs.

**Methods:** Using the 2016 National Study of Long-Term Care Providers, analyses included 3,305 ADSCs that documented ADs in participants' files. Bivariate and linear regression analyses were conducted.

**Results:** Nine states had a requirement to provide AD information. 80.8% of ADSCs provided AD information. 41.3% of participants had documented ADs. There were significant associations between state requirement, awareness, and providing information with AD prevalence. State requirement was mediated by awareness.

**Discussion:** This study found many ADSCs provided AD information, and ADSCs that thought their state had a requirement and provided information was associated with AD prevalence, regardless of state requirements.

### Keywords

health care policy; death and dying; long-term care; health services use

## INTRODUCTION

Advance directives (ADs), documents expressing end-of-life healthcare preferences, are an important component of care planning for individuals who require long-term care services. Having an AD can improve quality and satisfaction with care (Garrido, 2015) and reduce

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Author contributions:

All authors planned the study. J.P. Lendon and C. Caffrey conducted and verified statistical analyses. J.P. Lendon wrote the first draft of the paper and C. Caffrey and D.T. Lau provided substantial revisions.

Conflict of interest:

The authors declare that there is no conflict of interest.

end-of-life healthcare spending (Nicholas, 2011). There is a paucity of research on ADs in adult day services centers (ADSCs). ADSCs provide services to community-dwelling older adults with disabilities and adults with mental illness or intellectual/developmental disabilities. In 2016, 4,600 ADSCs served 286,300 participants, many with high levels of need; for example, about one quarter had activity of daily living limitations and one third had dementia (Lendon & Rome, 2017). ADSCs offer social and medical care to improve quality of life, reduce hospitalizations and nursing home admissions, and provide respite for caregivers (Fields, Anderson, & Dabelko-Schoeny, 2014). ADSCs may be an entrée to advance care planning by providing AD information and documentation to help facilitate communication and execution of participants' care preferences across health care settings (Coleman, 2003; Sinuff, et al. 2015).

Nursing homes, residential care communities, and home health agencies in the US are required by the Patient Self Determination Act (PSDA) (1990) to provide information about ADs; however, ADSCs are state licensed/certified and not all states have such requirements. Awareness of requirements, providing AD information, and prevalence of ADs among participants likely vary considerably due to different state requirements (O'Keeffe, O'Keeffe, & Shrethra, 2014). A recent report shows that about 38% of ADSC participants had an AD, which varied by region (Lendon, Caffrey, & Lau, 2019). The extent of ADSC directors/staff awareness of their state's requirement is unknown and may impact provision of AD information. Conversely, ADSCs may enact this practice regardless of state requirements. Little is known about whether providing information impacts the prevalence of ADs among participants. This report examines state requirements, awareness of state requirements, and the practice of providing AD information, and their associations with AD prevalence among participants.

## METHODS

### Data Source

Data are from the ADSC survey of the 2016 National Study of Long-Term Care Providers (NSLTCP), conducted by National Center for Health Statistics (NCHS). NCHS fielded a census using the National Adult Day Services Association's list of ADSCs in the U.S., regardless of membership. To be eligible for NSLTCP, ADSCs must (a) have been included in the database and in operation as of November, 2015; (b) be licensed or certified by the state to provide adult day services, accredited by the Commission on Accreditation of Rehabilitation Facilities, authorized/set up to participate in Medicaid, or part of a Program of All-Inclusive Care for the Elderly; (c) have an average daily attendance of one or more participants in a typical week; and (d) have one or more participants enrolled at the time of the survey. NSLTCP was multi-mode, using mail, web, and telephone follow-up. Response rate was 61.8%. Target respondents were ADSC directors (or a knowledgeable staff member), who were instructed to consult participants' records. There were two versions of the questionnaire with random assignment of ADSCs to each. Questions about ADs appeared in Version B. More details on NSLTCP are published elsewhere (NCHS, 2017).

The data were nationally representative of about 4,600 ADSCs. Of the 1,426 respondents (4,594, weighted) to Version B, the analytic sample was further restricted to 1,045 (3,305,

weighted) ADSCs that maintained documentation of ADs in participant files (78.1% of ADSCs). Exclusion was necessary to maintain the same denominator throughout all analyses because of an embedded skip pattern where NSLTCP collected the number of participants with ADs only from ADSCs that maintained documentation.

## Measures

**State Requirement and ADSC Awareness**—Determining a “state requirement” for ADSCs to provide AD information entailed reviewing several sources, beginning with the Assistant Secretary for Planning and Evaluation’s Regulatory Review of Adult Day Services: Final Report, 2014 Edition (O’Keefe, et al., 2014). The report was confirmed or supplemented by information from state ADSC associations and aging/public health agency websites, using the following search terms: advance directive, proxy, physician orders for life-sustaining treatments, medical orders for life-sustaining treatments, living will, and advance care planning. A state was considered to have a requirement if a source stipulated ADSCs must provide AD information to their participants and/or caregivers and was in effect before 2016 (Appendix A). Based on independent reviews by two authors (JPL and CC), there was 100% inter-rater agreement.

State requirement awareness was measured by: “Does your state require your center to provide information about ADs to participants or their families?” (yes/no/do not know). Awareness was collapsed to two categories for the multivariate analyses (yes/no and do not know).

**Providing AD information**—Providing AD information was measured by: “Advance directives are written documentation and may include health care proxies, durable power of attorney, living wills, do not resuscitate (DNR) orders, or physician or medical orders for life-sustaining treatments (POLST or MOLST). Does this ADSC provide any information about advance directives to participants or their families?” (yes/no).

**Participants with ADs**—The percentage of participants with ADs was based on two questions with a skip. The first question: “Does this adult day services center typically maintain documentation of participants’ advance directives or have documentation that an advance directive exists in participant files?” If yes, “Of the current participants, how many have documentation of an advance directive in their file?” The number of participants with an AD was converted to a percentage by dividing it by the total number of participants in the respective ADSC.

**Covariates**—Covariates included Census region, chain and ownership status, Medicaid licensure, electronic health records use, and model type. Chain status referred to ownership by a person, group, or organization with two or more ADSCs. Types of ownership included private nonprofit, private for profit or publicly traded or limited liability, and government. Medicaid licensure referred to ADSCs authorized or set up to participate in a Medicaid plan. Electronic health records use referred to use of computerized participant health/personal information. ADSCs were categorized as a medical model (designed to meet “only health/medical needs,” “primarily health/medical needs and some social/recreational needs,” or

“equally social/recreational and health/medical needs”) or social model (designed to meet “only social/recreational needs” or “primarily social/recreational needs and some health/medical needs”). ADSC size was the total number of participants.

## Analyses

Univariate and bivariate analyses were performed to describe the overall sample, using chi-square and t-tests and pair-wise tests, where applicable, for statistical significance. Multivariate linear regression examined the association between a state requirement and the percentage of ADSC participants with ADs (Model A). State requirement awareness was then entered into the model (Model B), to examine possible mediating effects, followed by providing AD information (Model C). Mediation of state requirement awareness was tested by bootstrapping the indirect effect and reporting bias-corrected 95% confidence interval (Hayes, 2009). Each model included all covariates.

Statistical significance tests were two-sided at  $p < 0.05$  significance level. Data analyses were performed using Stata/SE version 14 and complex survey weights to estimate robust standard errors. Univariate and bivariate analyses excluded missing cases on a case-by-case basis. Multivariate models excluded cases with missing data on any of the variables. Missing data ranged from 0.1% for medical model to 2.8% for the number of participants with ADs. Diagnostics showed no multicollinearity in the multivariate models.

## RESULTS

### State Requirement, Awareness, and Providing Information

Nine states had requirements for ADSCs to provide AD information, with 22.3% of ADSCs located in these states (Table 1). 39.2% of ADSCs thought their state had a requirement, 36.6% thought their state did not, and 24.3% did not know. In states with a requirement, 66.1% thought there was a requirement, compared to 31.4% in states without requirement. Overall, 80.8% of ADSCs provided AD information. In states with a requirement, 90.3% of ADSCs provided information, compared to 78.1% in states without a requirement.

### ADSC Participants with ADs

Overall, 41.3% of participants had an AD (Table 1), which did not differ by state requirement. Among ADSCs that thought their state had a requirement, 52.3% of participants had ADs, followed by 38.3% in ADSCs that did not know, and 31.1% in ADSCs that thought the state did not have a requirement (Table 2). Among ADSCs that provided information, 46.8% of participants had ADs, compared to 18.6% in ADSCs that did not.

Linear regression models of the percentage of participants with ADs are presented in Table 3. In Model A, state requirement had a statistically significant positive association with the percentage of participants with ADs ( $b=7.7$ ,  $SE=2.8$ ,  $p=.006$ ). Model B shows that state requirement awareness mediated the association between having a state requirement and the percentage with ADs. ADSCs that thought their state had a requirement ( $b=20.1$ ,  $SE=2.3$ ,  $p<.001$ ) had greater percentages of participants with ADs, compared to ADSCs that thought their state had no requirement or did not know. The direct effect of state requirement on AD

prevalence was no longer statistically significant ( $b=2.4$ ,  $SE=2.9$ ,  $p=.413$ ), but the indirect effect (5.4, BC 95% CI=3.3, 8.1), by way of awareness, was statistically significant.

Model C found that ADSCs that provided information ( $b=24.3$ ,  $SE=2.4$ ,  $p<.001$ ) had a greater percentage of participants with ADs, compared to ADSCs that did not provide information. Awareness ( $b=14.2$ ,  $SE=2.4$ ,  $p<.001$ ) was also still associated with percentage of participants with ADs.

## DISCUSSION

This study examined the associations between AD prevalence and having a state requirement for ADSCs to provide AD information to participants; ADSC's awareness of state requirements; and providing AD information. Despite the absence of a federal mandate and less than a quarter of ADSCs located in 9 states with a requirement, about 80% of ADSCs that documented ADs provided AD information and 41% of their participants had ADs.

A state requirement was associated with prevalence of ADs; however, this association was mediated by awareness. ADSC directors/staff that think there is a state requirement (despite incorrect perceptions of requirements) and providing AD information were important independent drivers of the prevalence of ADs, regardless of actual state requirements. These findings suggest ADSCs may believe providing AD information is a useful practice for many reasons, it is encouraged by other entities, or have other AD-related state requirements. For example, this practice may be influenced by Medicaid participation requirements, provider association recommendations, attitudes of ADSC owners/operators, or participants' health needs. ADSCs serve a unique population with complex healthcare needs who may benefit from advance care planning. This study suggests that educating participants about ADs may be positively associated with the percentage of participants with ADs.

This study has several limitations. The 2016 NSLTCP collected aggregated participant data; therefore, this study focused on regulatory and organizational factors and not individual-level sociodemographic/cultural/health characteristics that might also be related to having an AD. Analyses were restricted to only ADSCs that maintained AD documentation, which differ from ADSCs that do not document (Lendon, Caffrey, Lau, 2018), and might undercount participants with ADs. ADSCs that documented ADs were less likely to be in the West and more likely to be Medicaid licensed and to use EHRs. State requirements were based on independent reviews of secondary resources. Despite 100% agreement between the authors, regulations in some states might have been missed. The study could not determine if the survey respondent was unaware of a state requirement, whereas another employee might have been aware.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1.**Descriptive information overall and by state requirements to provide information about ADs to participants<sup>1</sup>

	All ADSCs (n=1,045)		ADSCs with state requirement <sup>2</sup> (n=237)		ADSCs without state requirement (n=808)	
	Percent	SE	Percent	SE	Percent	SE
ADSCs in states with requirements to provide information about ADs <sup>2</sup>	22.3	0.5	--	--	--	--
ADSC awareness about state requirement						
Thought state had requirement	39.2	1.2	66.1*	2.5	31.4	1.3
Thought state did not have requirement	36.6	1.2	17.7*	2.0	42.0	1.4
Did not know if state had requirement	24.3	1.1	16.2*	2.0	26.6	1.3
ADSCs that provided information about ADs to participants	80.8	1.0	90.3*	1.6	78.1	1.2
Participants with AD in files	41.3	1.1	45.2	2.4	40.1	1.2
U.S. Census Region						
Northeast	23.7	0.5	20.4*	1.1	24.7	0.6
Midwest	16.8	0.5	3.4*	0.2	20.6	0.6
South	36.0	0.6	64.2*	1.1	28.0	0.6
West	23.5	0.7	12.0*	0.5	26.8	0.9
ADSC characteristics						
Owned by a chain	42.3	1.3	37.1*	2.7	43.8	1.5
Nonprofit	54.9	1.2	38.6*	2.3	59.6	1.4
Medicaid licensed	82.0	0.9	88.5*	1.6	80.2	1.1
Used electronic health records	24.4	1.1	25.4	2.5	24.1	1.2
Medical model	59.2	1.2	71.8*	2.2	55.6	1.4

<sup>1</sup>The analytic subsample includes the 78% (weighted n=3,305) of ADSCs that maintained documentation of ADs in participants' files and excludes cases with missing data on a variable-by-variable basis.

<sup>2</sup>Appendix A provides details about the states identified as having language on requirements to provide information about ADs to participants.

\* Statistically significant differences between state requirement and no state requirement at  $p < 0.05$ .

Notes: AD = advance directive; ADSC = adult day services center; -- category not applicable

Source: NCHS, National Study of Long-Term Care Providers, 2016.



**Table 2.**

Percentage of ADSCs that provided information about ADs and percentage of participants with ADs, by state requirements, ADSC awareness, practice, US Census region, and ADSC operational characteristics<sup>1</sup>

	Provided information about ADs			Participants with ADs		
	Percent	SE	p-value	Percent	SE	p-value
State licensing requirement regarding ADs <sup>2</sup>						
State had language on requirement	90.3	1.6	0.000	45.2	2.4	0.060
No language on requirement	78.1	1.2		40.1	1.2	
ADSC awareness of state requirement						
Thought state had requirement	97.4	0.7	0.000	52.3	1.8	0.000
Thought state had no requirement	64.9	2.0		31.1	1.5	
Did not know if state had requirement	77.9	2.2		38.3	2.2	
ADSC practice						
Provided information about ADs	--	--	--	46.8	1.2	0.000
Did not provide information	--	--	--	18.6	1.8	
U.S. Census Region						
Northeast	80.2	2.0	0.000	46.6	2.1	0.000
Midwest	76.8	2.5		43.6	2.3	
South	89.9	1.3		40.4	1.8	
West	70.3	2.6		35.7	2.2	
ADSC characteristics						
Owned by a chain	77.1	1.7	0.003	39.5	1.6	0.282
Not a chain	83.3	1.2		42.4	1.4	
Nonprofit	80.2	1.4	0.613	41.1	1.3	0.915
For-profit	81.3	1.6		40.9	1.7	
Medicaid licensed	84.1	1.0	0.000	43.2	1.2	0.003
Not Medicaid licensed	66.1	3.0		33.0	2.5	
Used electronic health records	81.9	2.0	0.589	41.7	1.2	0.821
Did not use electronic health records	80.6	1.2		40.7	2.2	
Medical model	87.4	1.1	0.000	41.0	1.6	0.991
Social model	71.1	1.8		41.6	1.4	

<sup>1</sup>The analytic subsample includes the 78% (weighted n=3,305) of ADSCs that maintained documentation of ADs in participants' files and excludes cases missing data on a variable-by-variable basis.

<sup>2</sup>Appendix A provides details about the states identified as having language on requirements.

Notes: ADSC = adult day services center; AD = advance directive; SE = standard error; -- category not applicable

Source: NHCS, National Study of Long-Term Care Providers, 2016.



Table 3.

Linear regression models of percentage of participants with a documented AD<sup>1</sup>

	Model A			Model B			Model C		
	b	SE	p-value	b	SE	p-value	b	SE	p-value
State had language on requirement regarding ADs <sup>2</sup>	7.7	2.8	0.006	2.6	2.9	0.367	2.9	2.8	0.302
Awareness/Thought state had requirement	--	--	--	20.1	2.3	0.000	14.2	2.4	0.000
ADSC provided information about ADs to participants	--	--	--	--	--	--	24.3	2.4	0.000
U.S. Census Region									
Northeast (referent)	0.0	--	--	0.0	--	--	0.0	--	--
Midwest	-4.6	3.2	0.157	-1.6	3.1	0.612	-2.6	3.0	0.386
South	-9.4	2.9	0.001	-10.5	2.9	0.000	-12.9	2.8	0.000
West	-7.2	3.3	0.031	-7.1	3.2	0.028	-7.2	3.2	0.023
ADSC Operational Characteristics									
Owned by a chain	-1.7	2.2	0.420	-1.1	2.1	0.606	0.3	2.1	0.886
Nonprofit	-1.9	2.3	0.396	-0.9	2.2	0.675	-2.5	2.2	0.249
Medicaid licensed	9.5	2.9	0.001	7.2	2.9	0.012	4.7	2.7	0.083
Used electronic health records	0.4	2.5	0.891	-0.1	2.5	0.958	0.7	2.4	0.772
Medical model	-0.5	2.4	0.842	-3.6	2.3	0.125	-5.9	2.3	0.011
Number of participants	-0.1	0.0	0.000	-0.1	0.0	0.000	-0.1	0.0	0.000
Constant	44.4	4.2	0.000	40.9	4.1	0.000	28.3	4.1	0.000
R-squared percent	3.2			8.2			13.0		

<sup>1</sup> Analytic subsample of 78% (weighted, 3,305) of ADSCs that maintained documentation of ADs in participants' files. Missing data excluded.

<sup>2</sup> Appendix A provides details about the states identified as having requirements.

-- category not applicable

Notes: ADSC = adult day services center; AD = advance directive; b = beta coefficient; SE = standard error. Regression coefficients are adjusted.

Source: NCHS, National Study of Long-Term Care Providers, 2016.