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Advance Directive Documentation Among Adult Day Services Centers and Use Among Participants, by Region and Center Characteristics: National Study of Long-Term Care Providers, 2016

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Abstract

Objectives—This report describes the percentage of adult day services centers (ADSCs) that typically maintain documentation of participants' advance directives by region and center characteristics. Further, among ADSCs that maintain documentation, this report describes the percentage of participants with advance directives by region and center characteristics.

Methods—Data are from the ADSC component of the 2016 National Study of Long-Term Care Providers, a biennial survey conducted by the National Center for Health Statistics. The measures included whether the center typically maintains documentation of participants' advance directives and among those ADSCs with documentation, the percentage of participants with an advance directive. Differences in maintaining documentation and participants with advance directives by U.S. region and selected center-level characteristics were evaluated using two-sided chi-squared and *t* tests at the *p* less than 0.05 level.

Results—In 2016, 78.1% of ADSCs maintained documentation of advance directives, with the Northeast having the highest percentage among the U.S. regions. A higher percentage of Medicaid-licensed ADSCs maintained documentation of advance directives compared with ADSCs that were not Medicaid licensed. Among ADSCs that maintained documentation, about 38% of participants had an advance directive in their files. Small ADSCs had a higher percentage of participants with advance directives compared with medium and large ADSCs.

Keywords: care planning • home-based service • community-based service • Medicaid • electronic health record • nonprofit

Introduction

An advance directive is an important component in care planning for individuals with serious illnesses who require long-term care services and supports or end-of-life care. Advance directives are documents (including

those designating a health care decision maker/proxy/surrogate, do-not-resuscitate orders [DNRs], physician or medical orders for life-sustaining treatments, and living wills) that express patients' health care preferences in the event that they are unable to make decisions (1). Research shows that having an advance

directive may improve quality of care and satisfaction with care (2), reduce health care spending near the end of life (3), and result in more tailored end-of-life care in accordance with the individual's wishes.

The Patient Self-Determination Act (PSDA), passed in 1991, requires long-term care facilities and other health care providers that accept Medicare and Medicaid to provide information to residents about their rights to an advance directive and to maintain documentation of residents' advance directives in their files. Two years after the passage of PSDA, the percentage of facilities that maintained documentation showed a moderate increase, with considerable variation across 10 states (4). From 1990 to 1993, the prevalence of nursing home residents who had a DNR increased from 31% to 52%; those who had a living will increased from 4.2% to 13.3%; and those who designated a durable power of attorney increased from 7.6% to 19.5% (4). More than a decade later in 2004, 65% of nursing home residents had any type of advance directive (5). However, there is a wide range of prevalence rates among patients of other long-term care providers. In 2007, 28% of home health patients and 88% of hospice patients had an advance directive (5), and in 2016, 78% of residential care community



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residents had an advance directive (6). A 2010 study found that 26% of the general U.S. adult population had some form of advance directive (7).

Compared with other health care settings (e.g., nursing homes and hospitals), little is known about advance directive documentation practices in adult day services centers (ADSCs) and the prevalence of advance directives among ADSC participants. ADSCs are a home- and community-based sector of long-term care that provide an array of services, including structured activities, health monitoring, socialization, and assistance with activities of daily living for older adults with disabilities and adults with mental illness or intellectual and developmental disabilities. They offer valuable daytime social and medical care intended to improve quality of life, reduce rates of institutionalization, and provide respite for unpaid caregivers. ADSCs are regulated by states and are not mandated by PSDA to provide information on advance directives and maintain advance directive documentation. Documentation practices and the percentage of participants with advance directives will likely vary by region and center characteristics because of differences in state licensing requirements regarding advance directives in ADSCs (8) and the diverse operational characteristics of ADSCs across the United States (9).

This report describes the differences between ADSCs that typically maintain documentation of participants' advance directives by region and key center characteristics, and among ADSCs that maintain documentation, the percentage of participants with advance directives by region and center characteristics.

Methods

Data are from the ADSC component of the 2016 National Study of Long-Term Care Providers (NSLTCP), a biennial survey conducted by the National Center for Health Statistics (NCHS). The ADSC component is based on a census of ADSCs from the National Adult Day Services Association's database. The response rate was 62.4%, and analyses were adjusted for nonresponse bias. More details on the NSLTCP eligibility criteria,

design, and measures are published elsewhere (10). The data can be accessed through the NCHS' Research Data Center (<https://www.cdc.gov/rdc>).

Maintaining documentation of advance directives was measured by asking whether the center typically maintains documentation of participants' advance directives or has documentation that an advance directive exists in participants' files (yes or no). Analyses of documentation included all ADSCs that responded to this item.

Only the ADSCs that responded "yes" to maintaining documentation were asked about the percentage of participants with an advance directive with the following question, "Of the current participants, how many have documentation of an advance directive in their file?" The number of participants was converted to a percentage by dividing it by the total number of participants.

U.S. regions, characterized as Northeast, South, Midwest, and West, were investigated because of the variation in ADSCs and in the prevalence of advance directives in other long-term care settings by state and region. The center characteristics included size (small, medium, or large), Medicaid licensure status (licensed or not licensed), electronic health record (EHR) use (uses or does not use), and ownership type (nonprofit or for profit). These represent policy-relevant operational characteristics that may affect ADSCs' culture and resources regarding advance care planning. See the [Technical Notes](#) for more details about these variables.

The data are nationally representative of more than 4,600 ADSCs and 262,300 participants enrolled at the time of the NSLTCP survey in 2016. Analyses included 1,313 ADSCs that received the questionnaire version containing the advance directives items and responded to those items. More information on the survey methods and questionnaire versions is available from: https://www.cdc.gov/nchs/nsltcp/nsltcp_questionnaires.htm.

Cases with missing data were excluded from the analyses on a variable-by-variable basis. Missing data ranged from 0.4% for Medicaid licensure to 7.9% for whether an ADSC documents

advance directives. Differences were evaluated using chi-squared and *t* tests. All statistical significance tests were two-sided, using *p* less than 0.05 as the significance level, and statistically significant differences are indicated in the figures. Data analyses were performed using Stata/SE version 14 and SAS-callable SUDAAN version 11.0.0.

Results

Adult day services centers that maintain documentation of advance directives

- In 2016, 78.1% of all ADSCs maintained documentation of participants' advance directives ([Figure 1](#)).
- The highest percentage of ADSCs that maintained documentation of advanced directives was in the Northeast (92.9%), followed by the South (88.2%), the Midwest (77.6%), and the West (58.8%).
- A higher percentage of ADSCs licensed to accept Medicaid maintained documentation of advance directives (83.7%) compared with ADSCs that were not Medicaid licensed (60.2%) ([Figure 2](#)).
- A higher percentage of ADSCs that used EHRs maintained documentation of advance directives (84.9%) compared with ADSCs that did not use EHRs (76.4%).
- Percentages of ADSCs maintaining documentation were similar by center size and ownership type.

Percentage of participants with advance directives documented in their files

- Among the ADSCs that maintained documentation of advance directives (78% of all ADSCs), 37.7% of participants had an advance directive documented in their files ([Figure 3](#)).
- Higher percentages of participants with an advance directive in their files were located in the Northeast (45.6%), Midwest (41.0%), and South (39.6%) compared with the West (27.2%).

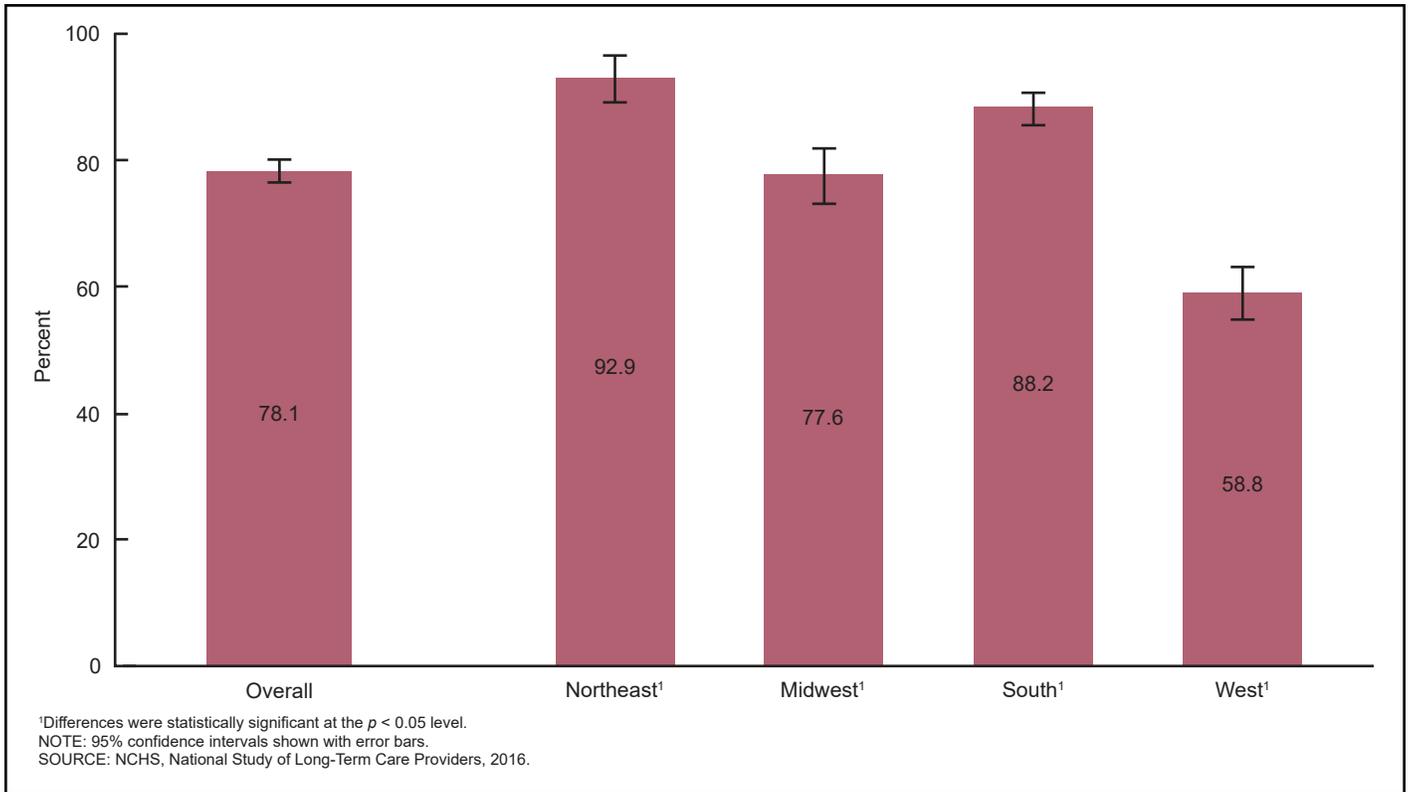


Figure 1. Percentage of adult day services centers that maintain documentation of participants' advance directives, overall and by United States region: 2016

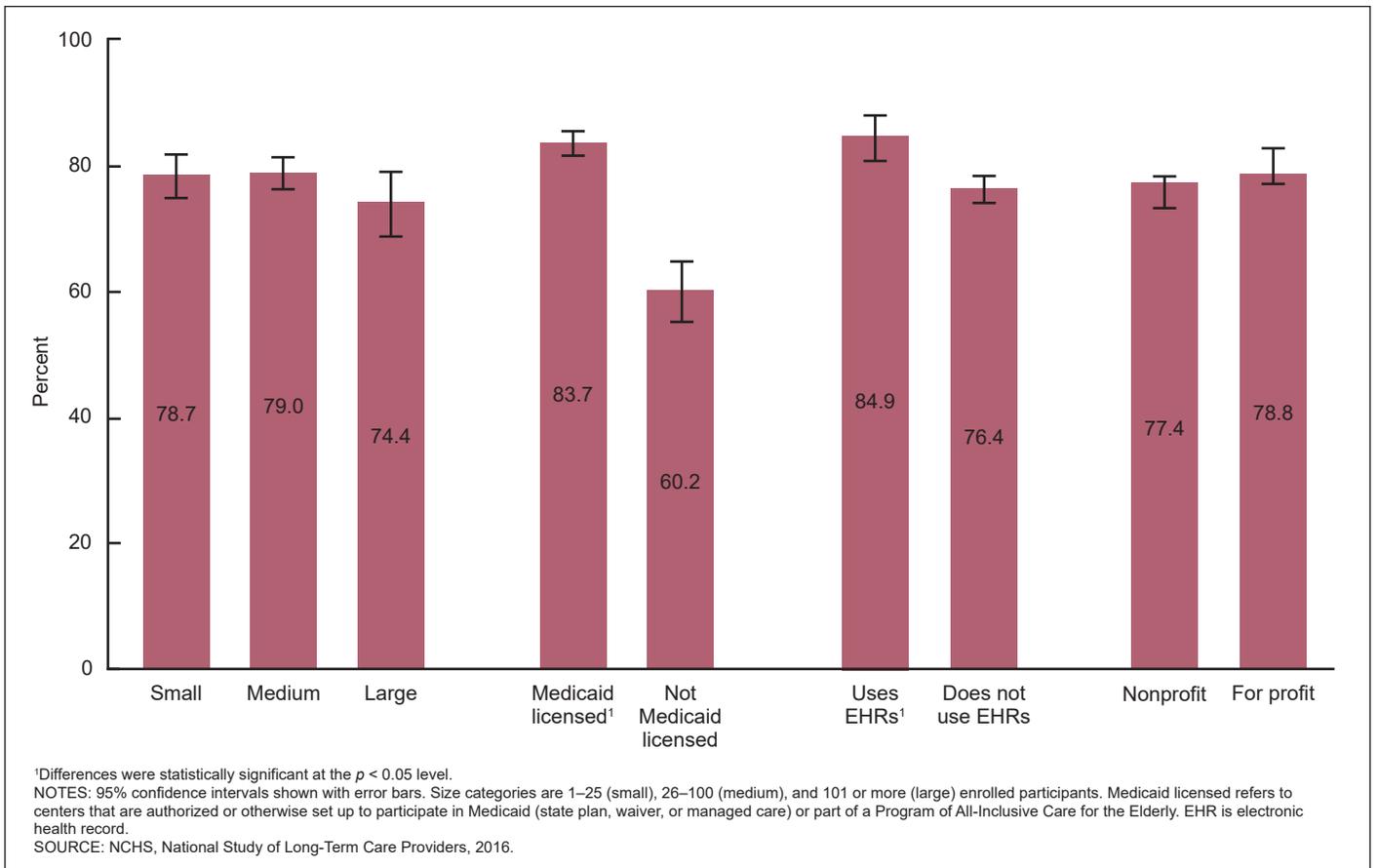


Figure 2. Percentage of adult day services centers that maintain documentation of participants' advance directives, by center characteristics: 2016

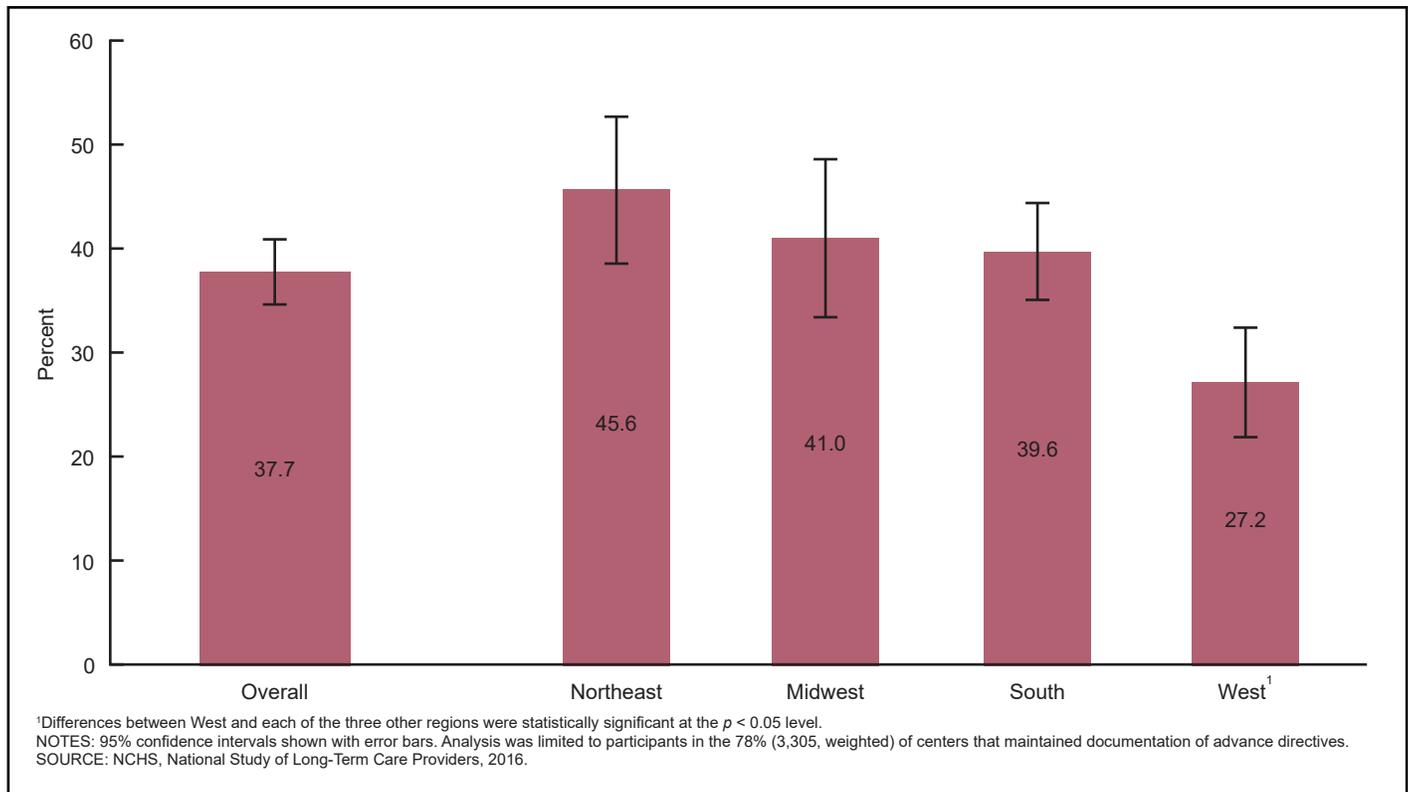


Figure 3. Percentage of participants with advance directives among adult day services centers that maintain documentation of advance directives, overall and by United States region: 2016

- Among ADSCs that maintained documentation of advance directives, smaller-sized ADSCs had the highest percentage of participants with advance directives in their files (48.1%) compared with medium (39.0%) and large (34.4%) ADSCs (Figure 4).
- In Medicaid-licensed ADSCs, a higher percentage of participants had an advance directive (40.4%) in their files compared with 22.4% in ADSCs that were not Medicaid licensed.
- Nonprofit ADSCs had a higher percentage of participants with advance directives in their files (41.5%) compared with for-profit ADSCs (34.5%).
- The percentage of participants with advance directives was similar in ADSCs maintaining documentation with and without EHRs.

Discussion

In 2016, approximately 78% of ADSCs in the United States reported that they typically maintained documentation of participants' advance directives.

However, there were differences in documentation practices across regions: About 93% of ADSCs in the Northeast maintained documentation, while 59% of ADSCs in the West maintained documentation. Advance directive documentation practices also varied by several of the selected center-level characteristics. Approximately 84% of ADSCs that were Medicaid licensed maintained documentation of advance directives compared with 60% of those that were not Medicaid licensed. In addition, 85% of ADSCs that used EHRs maintained documentation compared with 76% of ADSCs not using EHRs.

Among the 78% of ADSCs that maintained documentation, almost 38% of ADSC participants had an advance directive in their files. This percentage is higher than the most recent national estimates reported for the U.S. general adult population (26%) and home health patients (28%), and lower than nursing home (65%) and residential care community (78%) residents (5,6,7). Similar to the regional trend in documentation practices, fewer participants in the West (27%) had a documented advance directive compared

with about 40%–46% in other regions. There were size, Medicaid licensure, and ownership status variations in the percentage of participants with advance directives. Nearly one-half of participants in small ADSCs had an advance directive compared with medium (39%) and large (34%) ADSCs. Similar to the trend in documentation practices, Medicaid-licensed ADSCs had a higher percentage of participants with advance directives compared with those that were not Medicaid licensed. Nonprofit ADSCs had a higher percentage of participants with advance directives than for-profit ADSCs; however, there were no differences in maintaining documentation by ownership type.

This study is the first to show documentation practices of a nationally representative sample of ADSCs and the prevalence rates of advance directives among their participants. The center-level design of the 2016 NSLTCP allowed for examination of policy-relevant characteristics associated with advance directive practices and prevalence that can inform policy and research. However, this report is subject to limitations. For example, the estimate of participants with

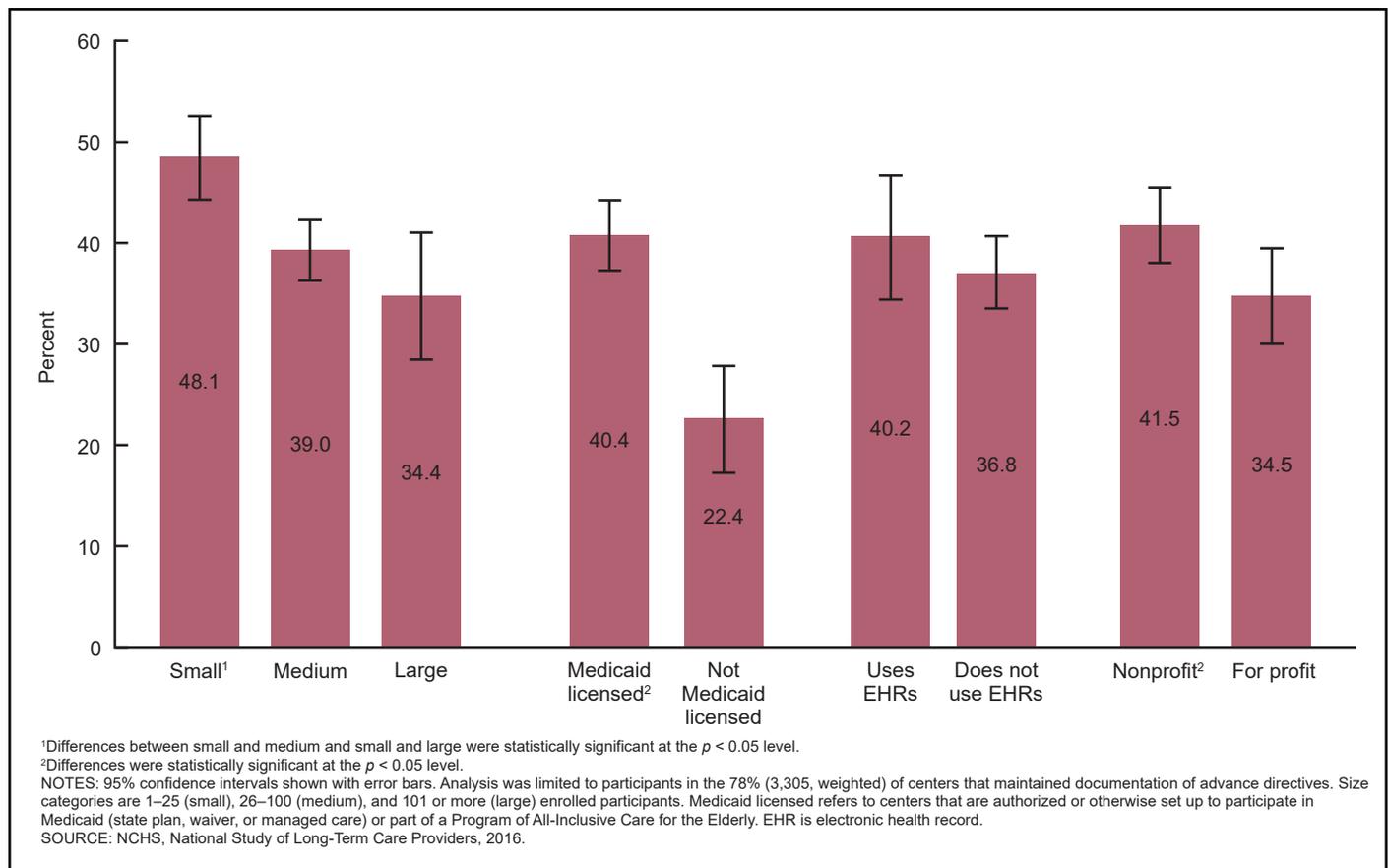


Figure 4. Percentage of participants with advance directives among adult day services centers that maintain documentation of advance directives, by center characteristics: 2016

an advance directive was collected only from ADSCs that reported maintaining documentation of advance directives, so the number of participants who may have an advance directive in ADSCs without documentation practices is unknown. Also, due to the aggregated participant information, this study was unable to examine the relationships between participant characteristics and the prevalence of having an advance directive.

The majority of ADSCs document advance directives, which may be an important part of ensuring individuals' end-of-life wishes are fulfilled, but only 38% of participants have a documented advance directive. These findings show policy-relevant differences regarding advance directives across U.S. regions and by key characteristics of ADSCs.

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Technical Notes

Definition of terms

Medicaid licensed—ADSCs that are authorized or otherwise set up to participate in Medicaid (state plan, waiver, or managed care) or part of a Program of All-Inclusive Care for the Elderly.

Ownership type—Categorization of ADSCs into two ownership types: for profit and nonprofit. For profit includes private for-profit ADSCs, publicly traded ADSCs, and limited liability ADSCs. Nonprofit includes private nonprofit ADSCs, as well as federal, state, county, and local government-owned ADSCs.

Participants of ADSCs—Those who were currently enrolled at the adult day services center on the day of data collection in 2016.

Size—Refers to ADSCs with 1–25 (small), 26–100 (medium), and 101 or more (large) enrolled participants.

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