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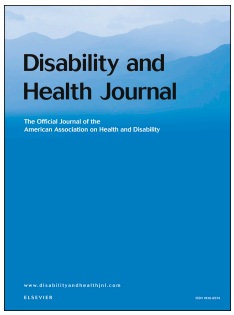

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State-Based Variations in Risk of Institutional Placement among Dually Eligible Non-Elderly Adults with Intellectual / Developmental Disabilities

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Abstract

Background Long-term services and supports (LTSS) include various paid institutional and personal care, comprising nearly 28.3% of Medicaid spending, with significant variability in home and community-based services (HCBS) eligibility across states.

Objective: To examine the impact of state of residence and HCBS spend on risk of institutional placement on a particularly vulnerable population, dual-eligible non-elderly adults with intellectual/developmental disabilities (IDD).

Methods: A retrospective cohort study was conducted to determine the hazard ratio of institutional placement based on Medicaid and Medicare data. We examined CMS Medicaid Analytic eXtract files with linked 2008-2012 Medicare data from California, Florida, New York, Ohio, and Pennsylvania. Eligible participants were 159,275 dual-eligible adults aged 18-to-64 years living in community settings who were continuously enrolled in Medicaid and had ICD-9 codes for ID in any inpatient, outpatient, or long-term encounter.

Results: Among study participants, 4.4% (n=6,975) had an eventual institutional placement claim. Subjects with institutional placement were more likely to be older, female, sicker, and have more claims for acute, ambulatory, and short-term care. In both unadjusted and adjusted analysis, risk of institutional placement was highest among those living in Ohio (HR 1.86 [1.70-2.04], P<0.0001) and California (HR 1.50 [1.37-1.64], P<0.0001) compared to Florida. Risk was lower for every $10,000 increase in HCBS spend at baseline. Black, Hispanic, and Other subjects had lower risks than While subjects,

Conclusions: Our findings suggest that continued investments in HCBS and better access may decrease reliance on costly institutional care for non-elderly disabled adults who may need long-term care for decades.

Keywords: Medicaid, Public Health Systems Research, Health Expenditures, Intellectual Disability, Residential Facilities, Home Care Services, Community Health Services

Introduction

Long-term services and supports (LTSS) encompass a broad range of paid institutional, medical and personal care used by approximately 4.8% of Medicaid beneficiaries who are disabled or elderly;[1] LTSS accounts for nearly 28.3% of all Medicaid spending and is one of the fastest growing portions of state Medicaid budgets.[1,2] Although Medicaid is required to cover skilled nursing facilities and other long-term placements nationally, eligibility and benefits covered for home and community based services (HCBS), along with the services that allow people with disabilities to remain in community settings can vary tremendously by state.[3–6] Most people requiring LTSS prefer to remain in community settings rather than enter institutional settings;[7] particularly after nursing homes, group homes, and other institutional settings became the "ground zero" of COVID-19 infections and deaths.[8]

LTSS costs account for 62% of Medicaid expenditures for beneficiaries who are dual eligible for both Medicaid and Medicare.[3] Patterns of long-term care use by people with intellectual/developmental disabilities (IDD) is an important indicator of the impact of state-based policies of HCBS on people with disabilities. An estimated 7 to 8 million individuals in the US have an intellectual disability.[9] People with IDD are often dependent on other caregivers for basic and instrumental activities of daily living. Consequently, many currently need, or will eventually need, LTSS, which are typically provided by Medicaid and Medicare sponsored programs. Because of the increasing and near normal lifespan of people with IDD,[10,11] most people with IDD will require LTSS for many decades. Furthermore, these individuals rely on Medicaid for LTSS costs. In 2014, $42 billion was spent on LTSS for people with IDD, nearly 30% of total LTSS spending.[12] Though the total number of people with IDD is relatively small, the total number is growing, and people with IDD typically require long-term HCBS;

consequently, the impact of HCBS on eventual institution-based placement can be identified. Waiting lists for HCBS continue to grow nationally; most people on waiting lists are people with IDD.[12] Furthermore, approximately 41% of non-elderly adults (<65 years) with disabilities are dually eligible for Medicare and Medicaid, a known group with high overall spending.[13]

In this study, we aimed to address three key questions: First, does the risk of institutional placement vary by state of residence among dually-eligible non-elderly adults with IDD? Second, what is the relationship between HCBS spending and institutional placement risk? Finally, are there demographic disparities in institutional placement risk? Our goal was to identify whether and how state policies and HCBS investments influence long-term outcomes for this vulnerable population. Eligibility for and eligible LTSS covered services in community settings are set by each state's Medicaid policy, which varies from state to state.[14] Unknown is whether institutional placements vary by state and HCBS spending. Considering the NIH 2023 mission statement,[15] which now includes people with disabilities as a populations facing health disparities, our study aims to align and aid NIH research for this population. In this study, our goal was to identify whether the risk of institutional placement varied by state of residence and spending in HCBS among Medicaid and Medicare dually eligible non-elderly adults with IDD.

Methods

We conducted a retrospective cohort study using the Centers for Medicare and Medicaid Services (CMS) Medicaid Analytic eXtract (MAX) data files from California, Florida, New York, Ohio, and Pennsylvania with linked Medicare data from 2008 to 2012. The years for analysis were chosen for three main reasons. Firstly, long-term claims in many states were no longer itemized in subsequent years as states began moving LTSS to managed care, making analysis of long-term care costs more challenging. Secondly, we aimed to examine the dynamic

of Medicaid funding before COVID-19 Public Health Emergency (PHE) funding was implemented.[16] Examining HCBS systems before COVID-19 PHE funding was introduced allows for analyses to reflect potential HCBS systems post-PHE funding. Thirdly, MAX files used provide a complete and reliable source of LTSS specifically, compared to the new TAF-RIF files. Established methods for identifying specific LTSS supports in MAX files are published and used widely. However, these methods are not fully transferrable to TAF-RIF files.[17]

Participants were included if 18 to 64 years old (at time of the index year), dually eligible for Medicare and Medicaid benefits, were continuously enrolled in Medicaid (defined as 10 of 12 months) in each year of enrollment, and had any one of the following ICD-9 diagnostic codes for intellectual disability in any inpatient, outpatient, or long-term encounter: autism (299*); intellectual disability (317, 317.1, 318.00, 318.1, 318.2, 319); Cerebral palsy (343, 343.1, 343.2, 343.4, 343.8, 343.9); spina bifida (741, 741.01, 741.02, 741.03, 741.9, 741.91, 741.93); Down syndrome (758.00, 758.1, 758.2, 758.3, 758.31, 758.32, 758.33, 758.39, 758.4, 758.5, 758.6, 758.7, 758.8, 758.81, 758.89, 758.9); tuberous sclerosis: Bourneville's disease (759.5); Fragile X syndrome (759.83), or fetal alcohol syndrome (760.71).[18,19] The study focused on dual-eligible beneficiaries because they represent a particularly vulnerable population with high healthcare needs, account for a disproportionate share of LTSS spending, and their dual coverage allows more complete capture of healthcare utilization and outcomes through both Medicare and Medicaid claims. We excluded 25.645 individuals (13.87% of initial cohort) who were already enrolled in a long-term care institution setting for 90+ days at baseline.

Description of Variables

The primary outcome was the first long-term institutional placement after the baseline year of 2008, defined as the presence of at least one Medicaid claim for services received in a

nursing facility or intermediate care facility for individuals with intellectual disabilities (ICF-IID) for three months or longer,[20] obtained from the Long-Term Care files of MAX data files. ICF-IID are residential facilities covered by Medicaid designed for individuals with intellectual disabilities, which include large state-based institutions and smaller group homes. Individuals with claims for long-term institutional placement in a nursing facility or an ICF-IID in the baseline year 2008 were excluded. The primary exposure measure was state of residence (California, Florida, New York, Ohio, or Pennsylvania); the secondary exposure measures were race and cost of HCBS (total cost of durable medical equipment, home health aide, home nursing services, case management services, environmental modifications) in the baseline year 2008, which was calculated from claims in the MAX Long-Term Care files and Medicare files.

Acute and ambulatory utilization covariate measures during the baseline year included short-term (<3 months) nursing home or ICF-IID stays,[21,22] medical and psychiatric hospitalizations, ambulatory office visits, and ED encounters. Other covariates included Medicaid or Medicare eligibility status; demographics (age, gender); comorbid conditions or medical complexity (Charlson Comorbidity Index),[23,24] number of Complex Chronic Conditions,[25,26] presence of mental health diagnosis (schizophrenia [295], bipolar disorder [296.00-296.10, 296.36-296.89], depression [296.20-296.35, 311], anxiety disorder [300.00-300.29, 301.4], conduct disorder [312.00-313.89], attention deficit disorder [314], mental disorders due to conditions classified elsewhere [293, 294], delusional disorders [297], other nonorganic psychosis [298], dissociative and somatoform disorders [300.10-300.19, 300.30-300.99], personality disorders [301.10-301.30, 301.50-301.99], special symptoms or syndromes not elsewhere classified [307], acute reaction to stress [308], adjustment reaction [309], and disturbance of emotions specific to childhood and adolescence [313.90-313.99]); and

polypharmacy (eight or more different drugs prescribed in the baseline year). All covariates were measured at baseline.

Statistical Analyses

The primary outcome, incidence of long-term institutional placement, was coded both as the time in years from the start date of follow-up to the earliest of institutional placement (event of interest) or end of study (censored). In preliminary analysis, baseline characteristics were compared between those with and without eventual institutional placement using Chi square tests for categorical variables and t-tests for continuous variables which appeared normally distributed, or Wilcoxon rank sum tests for continuous variables with a skewed distribution. Cox proportional hazards regression models were used to compare the time to long-term institutional placement for each independent variable. Independent variables associated with institutional placement, with a p-value of <0.2, were included in a multivariable Cox regression model. Because complex chronic conditions and the Charlson Comorbidity Index (CCI) were included in the model, collinearity was a possibility. The standard errors of the parameter estimates were examined to determine if multicollinearity exists (if any of the standard errors are large). Analyses were performed in SAS version 9.4 (SAS Institute, Cary, NC), with two-sided tests of hypotheses and a p-value < 0.05 as the criterion for statistical significance.

This study was considered exempt by the Northwell Health Institutional Review Board.

Results

A total of 159,275 individuals who were dually eligible with IDD met inclusion and exclusion criteria with claims from NY, PA, OH, FL, and CA between 2008 and 2012. The overall cohort had a mean age of 41.3 years (SD=11.4, range 19-65 years), 56.9% were male, 29.3% were non-white; they lived in CA (28.3%), FL (12.7%), NY (26.0%), OH (16.6%), and

PA (16.4%). Of those, 4.4% (n=6,975) had a long-term care placement claim. In bivariate analysis comparing individuals with and without an eventual institutional placement claim at baseline, those individuals with institutional placement were on average 7.9 years older (48.9 years vs. 41.0 years, P<0.0001)) and more likely to be female (44.6% vs. 43.0%, P<0.01) and White (76.8% vs. 70.4%, P<0.0001). They were generally sicker and more medically complex, with higher mean Charlson Comorbidity Index (1.6 vs 0.8, P<0.0001), greater polypharmacy (66.4% vs. 44.7%, P<0.0001), more emergency room visits (2.1 vs. 1.0, P<0.0001), more total days in the hospital (8.2 vs 2.1, P<0.0001), and had at least one short-term (<90 days) nursing home or ICF-IID stay (5% vs 0.9%, P<0.0001) (Table 1). Total mean HCBS cost was lower among those with eventual institutional placement compared to those without ($21,087 vs. $25,055, P<0.0001) (Table 1).

In unadjusted Cox models, the hazard ratio of placement in a long-term care facility by state was highest among those living in Ohio compared to Florida (HR 1.86 [1.70-2.04], P<0.0001), followed by California (HR 1.50 [1.37-1.64], P<0.0001), Pennsylvania, and New York (Figure 1). After adjustment for demographic characteristics, clinical risk factors, and HCBS spending (Figure 2), the risk of placement not only remained significant, but was amplified, with an increased risk for long-term placement among those living in Ohio (HR 2.12 [1.92, 2.34], P<0.0001), California (HR 1.68 [1.53, 1.84], P<0.0001), and New York (HR 1.56 [1.41, 1.72], P<0.0001), compared to Florida. As expected, higher Charlson Comorbidity Index, greater ED visits, and presence of polypharmacy were all significantly associated with increased risk of long-term placement.

Higher total cost of HCBS at baseline was associated with a decreased risk for long-term placement compared to a lower total cost of HCBS in both unadjusted and adjusted models. In

adjusted models, for every $10,000 increase in HCBS total cost, the risk of institutional placement was lower (HR 0.97 [0.97-0.98], P<0.0001). Because of the distribution of HCBS costs, we also ran the analysis categorizing HCBS cost by standard deviations above the mean of $24,880. Compared to those without HCBS claims, individuals with HCBS spend within two standard deviations ($73,156-$121,431) and three standard deviations (>$121,431) above mean HCBS spending were associated with the lowest risk of institutional placement: (HR 0.76 [0.67-0.86], P<0.0001) and (HR 0.59 [0.51-0.67), P<0.0001) respectively (Figure 2).

There were differences in risk of institutional placement by race in both unadjusted and adjusted analysis. Compared to White subjects, those who were Black (HR 0.88 [0.82, 0.94], P=0.0003), Hispanic (HR 0.77 [0.68, 0,86], P<0.0001), other (HR 0.77 [0.68, 0,88], P<0.0001), or unknown race (HR 0.69 [0.59, 0.81], P<0.0001) had lower risk of institutional placement in adjusted analysis (Figure 2). However, risk of institutional placement by race also varied by state, with higher risk of institutional placement among Hispanic compared to White subjects in NY and PA.

Discussion

This study had three primary findings. First, among dually eligible non-elderly adults with IDD, 4.4% had a long-term care placement claim within four years, with significant variation in risk for long-term placement across states: Ohio had over a two-fold risk of institutional placement compared to other states, even after adjustment for clinical factors such as age, number of comorbid conditions, and polypharmacy. Second, risk of institutional placement decreases with every $10,000 increase in HCBS expenditures. And finally, we found significant racial disparity in risk of institutional placement, with the highest risk among Caucasian individuals, suggesting that there might be racial or cultural factors affecting decision-making

around institutional placement, or that access to institutional settings may vary by racial or ethnic groups.

Our findings also suggest that continued investments in HCBS and improvements in access to HCBS will decrease reliance on more costly and less desirable institutional settings for the long-term care of non-elderly disabled populations, who rely on formal long-term care support for many decades due to their age. Early investments and improved access to Medicaid HCBS may help states keep Medicaid and developmental disability services budgets more balanced in the long-run, allowing non-elderly disabled adults to age-in-place in preferred community settings. Furthermore, people receiving services through HCBS have improved health outcomes compared to those receiving care in institutional settings.[27]

The inverse relationship between HCBS spending and institutional placement risk likely reflects several mechanisms. Higher HCBS spending typically translates to more comprehensive support services that enable individuals to remain safely in their homes and communities. These support services can include personal care assistance, home modifications, respite care, and case management. When HCBS funding is insufficient, individuals with IDD and their families may not have sufficient support for activities of daily living, proper supervision, or necessary home modifications, potentially creating unsafe situations that necessitate institutional placement. Additionally, higher HCBS spending often indicates better access to preventive services and care coordination, which can help prevent health crises that might otherwise lead to institutional placement. This is particularly relevant for individuals with IDD who often have complex medical and support needs. If these medical support needs are unmet in community settings, institutional placement may be necessary. Our finding that individuals with eventual institutional placement had lower baseline HCBS spending suggests that insufficient community-based

support may create circumstances where institutional care becomes the only viable option for meeting an individual's care needs.

Our findings also suggest that state-specific Medicaid policies that define eligible disabled populations and covered HCBS will influence the access to HCBS and demand for institutional care for non-elderly disabled populations.[4–6,28] During the study period, states varied considerably in their HCBS approaches. While Ohio dedicated over half its LTC Medicaid budget to institutional settings, other states had made substantial shifts toward HCBS. For example, California implemented multiple HCBS waivers specifically for individuals with developmental disabilities, while New York emphasized managed care approaches to HCBS delivery. Florida maintained a more traditional fee-for-service model, while Pennsylvania implemented a mix of managed care and fee-for-service approaches.[29] In our study, Ohio had the highest risk for institutional placement among non-elderly adults with IDD compared to New York, Pennsylvania, Florida, and California. In 2008, Ohio ranked 43rd out of 50 U.S. states in institutional to community expenditure ratio: more than half of Ohio's LTC Medicaid budget was dedicated to institutional settings for individuals with IDD.[30,31] Compared with other states who had substantially decreased their budgets dedicated to institutional settings, Ohio lagged behind and had a greater proportion of state budget dedicated to institutional settings compared to HCBS for individuals with IDD.[31] Furthermore, the Ohio Home Care Waiver was designed initially for those with physical disabilities only, precluding access to those with mental illness and IDD.[31] Therefore, adults with IDD did not have access to HCBS and were more likely to require Ohio nursing homes.[31] Given the high prevalence of comorbid mental health disorders among adults with IDD, the large variation in access to mental and behavioral health waiver services by state may further contribute to institutionalization risk.[28] The wide variation in HCBS

costs reflects differences in state Medicaid policies, available waiver programs, and coverage limits.[32] While states implement cost caps through their waiver programs, these caps vary significantly by state and service type, contributing to the observed variations in HCBS spending.[33]

Finally, we found significant racial disparity in institutional placement between white and non-white populations, with white individuals with IDD having higher risk for institutional placement than Black, Latino, Asian and other non-white individuals. This finding may suggest that there may be difficulties accessing institutional care by race, or that there are racial or cultural differences in preferences around institutional care among people with IDD. This finding may also reflect racial disparities in access to full-dual Medicaid and Medicare benefits among adults with disabilities, where more white adults are full-dual eligible for both Medicare and Medicaid compared to Black, Asian/Pacific Islander and Hispanic beneficiaries.[34] The literature around racial disparities in institutional placement risk among a more general population is mixed. Historically, minorities were less likely to use a nursing home,[35] recent trends have shown the reverse.[38,39] Potential reasons for this shift is a faster growth of minority populations, less HCBS access for minorities, and the growth of assisted living communities which are costly and paid privately. All these trends appear to increase segregation of white individuals with greater ability to pay privately in assisted living communities and non-white individuals in nursing homes, nearly all of which accept Medicaid.[36,37] Whether this trend holds true among non-elderly disabled adults, or the subgroup of those with IDD, is unknown.

The COVID-19 pandemic prosed new challenges to HCBS delivery. To address these issues, PHE budgets for Medicaid HCBS program budgets were implemented, allowing states to strengthen service delivery through temporary funding increases.[38] Increases in HCBS funding

have been shown to improve patient outcomes as well as reduce risk of being institutionalized.[39] The loss of PHE funding and the flexibility that came with it may exasperate challenges seen in service delivery and the quality of HCBS. Return to post-PHE policies may further exacerbate the disparities described in these results.

A notable aspect of our study is the use of MAX files, which were phased out in 2015,[40] compared to current CMS external files, TAF RIF. MAX and TAF RIF files differ in data-cleaning rules and who is responsible for the data. MAX file production included data cleaning rules, as well as extensive validation and data quality reviews at the federal level. TAF RIF files include fewer data cleaning rules and states are responsible for the quality of their data.[41] Beyond the contribution past data can have on upcoming policy changes, data quality of MAX files shows the need for changes to the TAF RIF files to mitigate the issues that arise when trying to identify HCBS accurately among the data files. In a time marked by significant policy shifts, acknowledgment of these data issues can be important for future data use.

This study has some limitations. These findings may not necessarily reflect current Medicaid state policies or institutional placement risk of specific states. Because many states implemented managed care for their LTSS in subsequent years,[42] we would not have been able to itemize the costs in Medicaid long-term care files as easily. This study only included dual-eligible adults with IDD and may not necessarily be generalizable to those who are Medicaid only beneficiaries due to not having direct access to HCBS in any particular region. Access to home care agencies, assisted living, and other residential services varies by region. In many states during this period, there were long state-specific wait lists for HCBS, particularly for those with IDD. Additionally, although Medicare administrative data is fairly accurate in identifying people who affiliate with White or Black racial groups, these administrative claims data is less

accurate for all other racial groups or for Hispanic/Latino origin.[43] Finally, use of pre-pandemic data might not accurately show what is to be expected in upcoming years regarding HCBS. While Covid-19 pandemic policies have left states with gaps in funding, it has shown the impact funding and emergency service can have HCBS. Uncertainty of state decisions in the aftermath of PHE funding loss may cause discrepancies in service coverage depending on state's ability to run services and programs without PHE funding.

Nonetheless, this study provides important findings on variability in the risk of institutional placement by state among non-elderly adults with IDD, four-year institutional placement risk based on early state-dependent HCBS investments, and the presence of racial disparities in institutional placement risk. These findings may be particularly consequential given the length of time adults with IDD need long-term care and the relatively early age at which they enter institutional care. Our findings may help state Medicaid agencies and state developmental disabilities services to better predict the impact of current HCBS investments on 4-year institutional placement risk of these vulnerable adults post-pandemic.

Declaration of generative AI and AI-assisted technologies in the writing process

The authors did not use AI or AI-assisted tools during the preparation of this work.

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Table 1. Baseline Characteristics of Dually-Eligible Non-Elderly Adults with Intellectual/Developmental Disabilities With and Without Long-term Institutional Placement Claims

Variable	No Long-term Placement (n=152,300)	Long-term Placement (n=6,975)	P-value
Age at baseline, M(SD)	41.0 (11.3)	48.9 (9.6)	0.0000
Sex, No. (%)			0.0079
Female	65,518 (43.0%)	3,113 (44.6%)	
Male	86,782 (57.0%)	3,862 (55.4%)	
Race, No. (%)			<.0001
White	107,294 (70.4%)	5,355 (76.8%)	
Black	21,510 (14.1%)	890 (12.8%)	
American Indian Or Alaskan Native	384 (0.3%)	15 (0.2%)	
Asian Or Pacific Islander	1,499 (1.0%)	52 (0.7%)	
Hispanic	10,848 (7.1%)	349 (5.0%)	
Native Hawaiian Or Other Pacific Is	1,684 (1.1%)	53 (0.8%)	
Hispanic Or Latino And One Or More	3,876 (2.5%)	112 (1.6%)	
Unknown	5,205 (3.4%)	149 (2.1%)	
State, No (%)			<.0001
California	42,887 (28.2%)	2,173 (31.2%)	
Florida	19,558 (12.8%)	636 (9.1%)	
New York	39,750 (26.1%)	1,614 (23.1%)	
Ohio	24,970 (16.4%)	1,516 (21.7%)	
Pennsylvania	25,135 (16.5%)	1,036 (14.9%)	
Short-term (<3 months) nursing home or ICF-ID stay, No (%)	1,418 (0.9%)	346 (5.0%)	<.0001
Inpatient stay, No (%)			<.0001
None	131,088 (86.1%)	4,645 (66.6%)	
1 or more	21,212 (13.9%)	2,330 (33.4%)	
Number of ambulatory care visits, Median (Q1-Q3)	11.0 (3.0-25.0)	15.0 (5.0-34.0)	<.0001
Number of ED visits, Median (Q1-Q3)	0.0 (0.0-1.0)	1.0 (0.0-2.0)	<.0001
Home and Community Based Services total costs			
Median (Q1-Q3)	3454.0 (146.0-25629.0)	3644.0 (162.0-23167.0)	0.1399
Mean (SD)	25,054.5 (48,559.8)	21087.3 (41408.2)	0.0000
Charlson comorbidity index, Mean (SD)	0.8 (1.1)	1.6 (1.7)	0.0000
Number of Complex Chronic Conditions, Mean (SD)	1.2 (1.2)	1.8 (1.4)	0.0000
Autism, No (%)	8,993 (5.9%)	219 (3.1%)	<.0001
Other mental health diagnosis, No (%)	45,339 (29.8%)	2,740 (39.3%)	<.0001
Polypharmacy (8 or more different drugs in 1-year baseline period), No (%)	68,043 (44.7%)	4,629 (66.4%)	<.0001
Number of psychiatric drug types prescribed during 1-year baseline period, Mean (SD)	1.4 (1.6)	2.0 (1.8)	0.0000

Figure Headers

Figure 1: Hazard ratios are presented on a log scale. Adjusted models include demographic characteristics (age, sex, race), clinical risk factors (Charlson Comorbidity Index, polypharmacy, ED visits, mental health diagnoses), and baseline HCBS spending.

Figure 2. Kaplan-Meier Failure Estimates of Institutional Placement Risk Among Dually-Eligible Non-Elderly Adults with Intellectual/Developmental Disabilities by State of Residence (A), Home and Community Based Services (B), and Race/Ethnicity (C)

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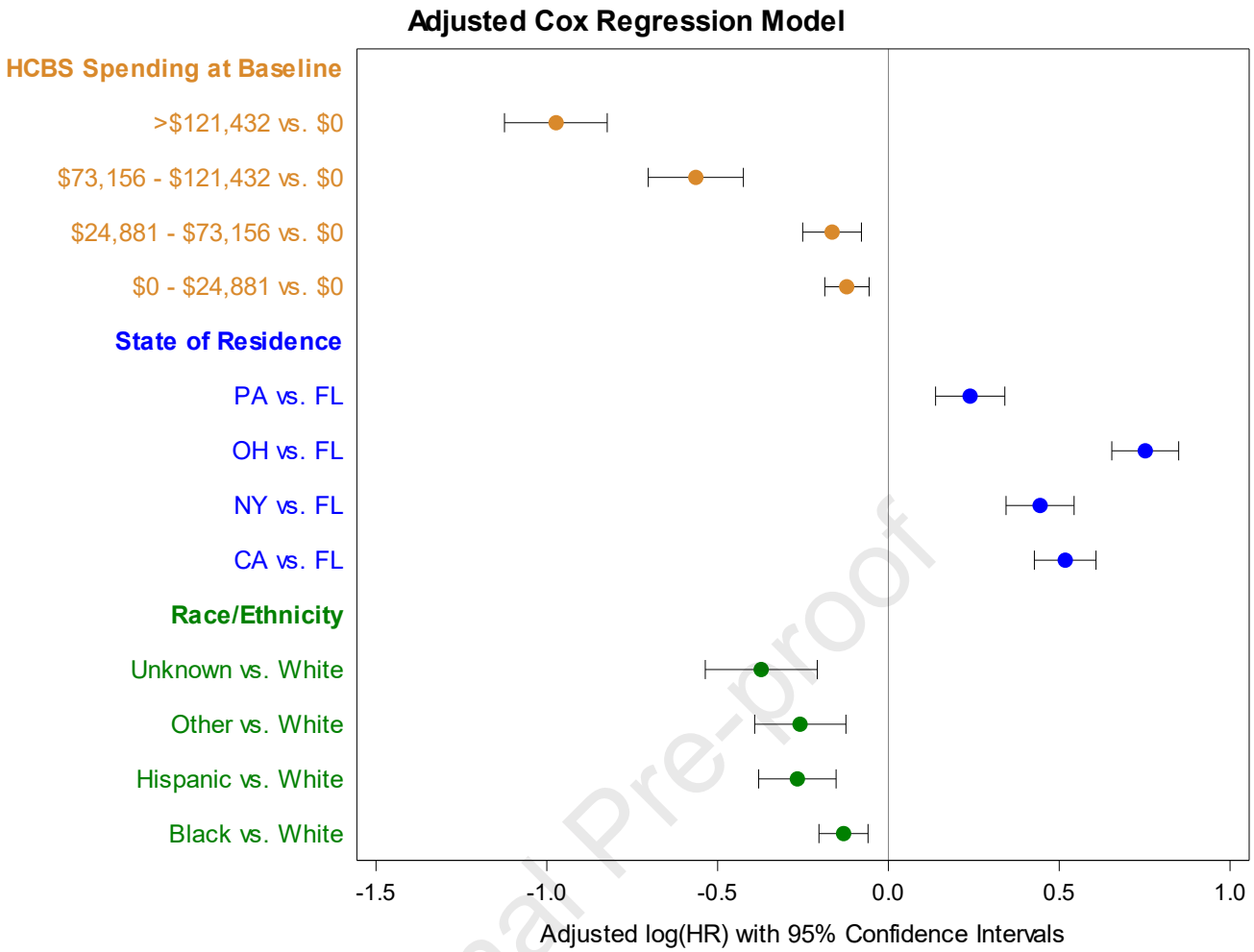

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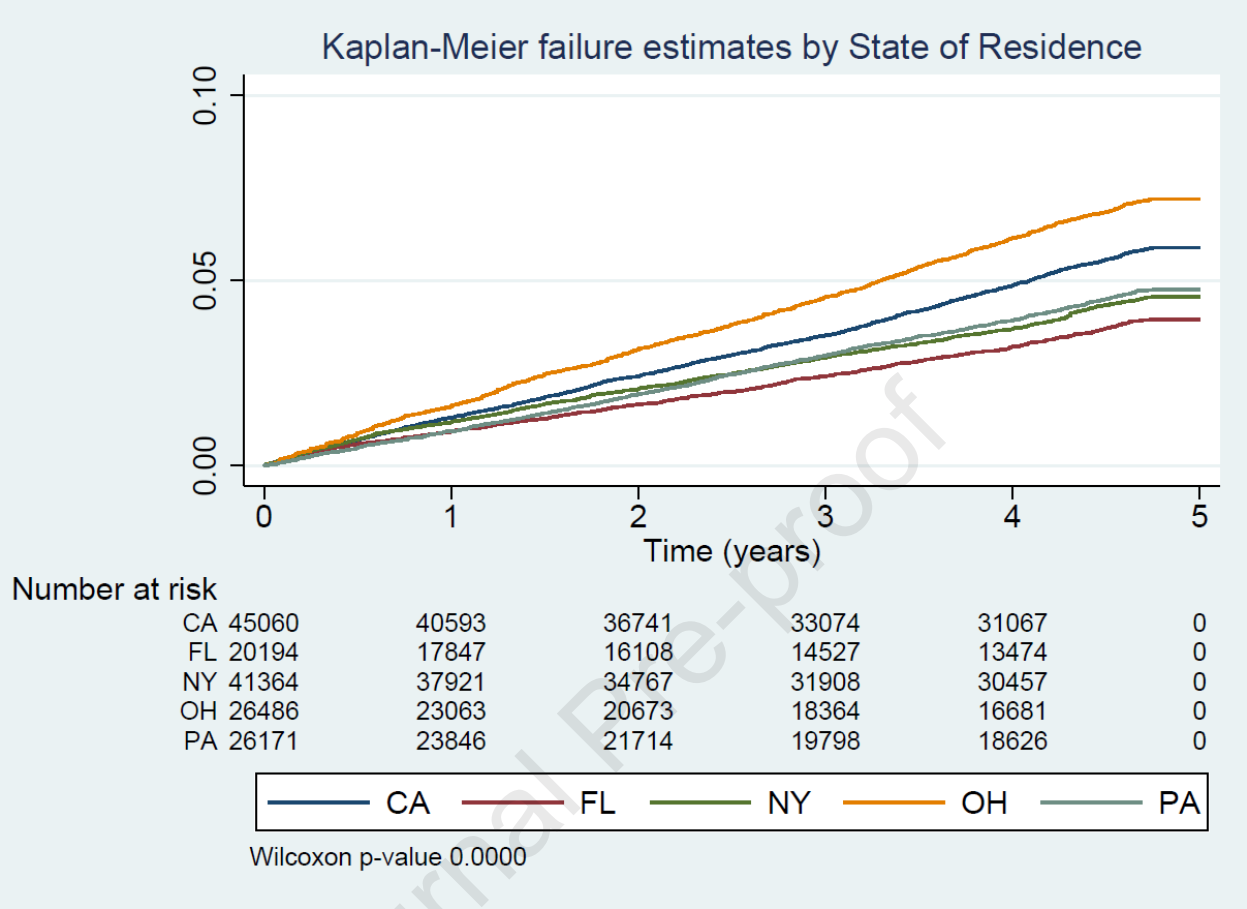

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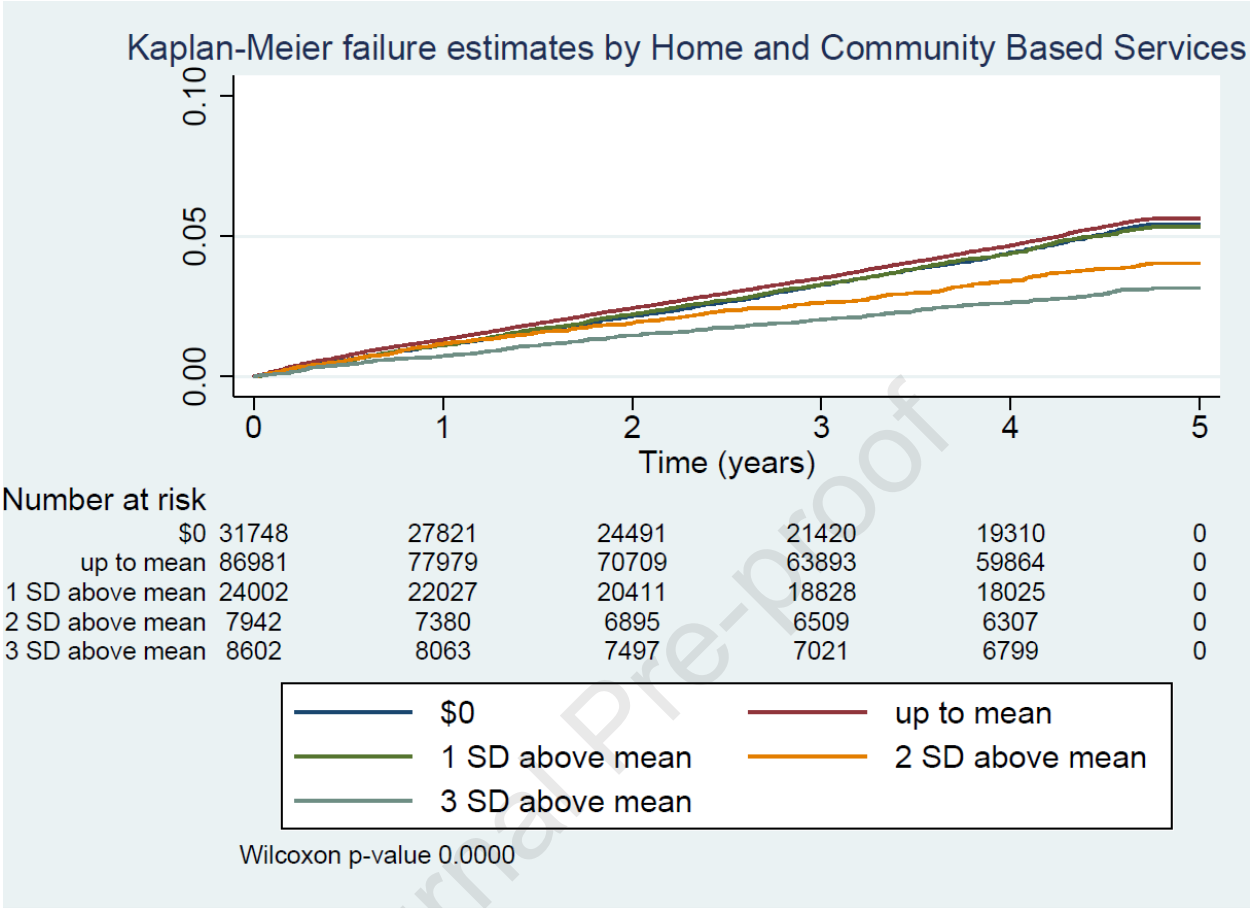

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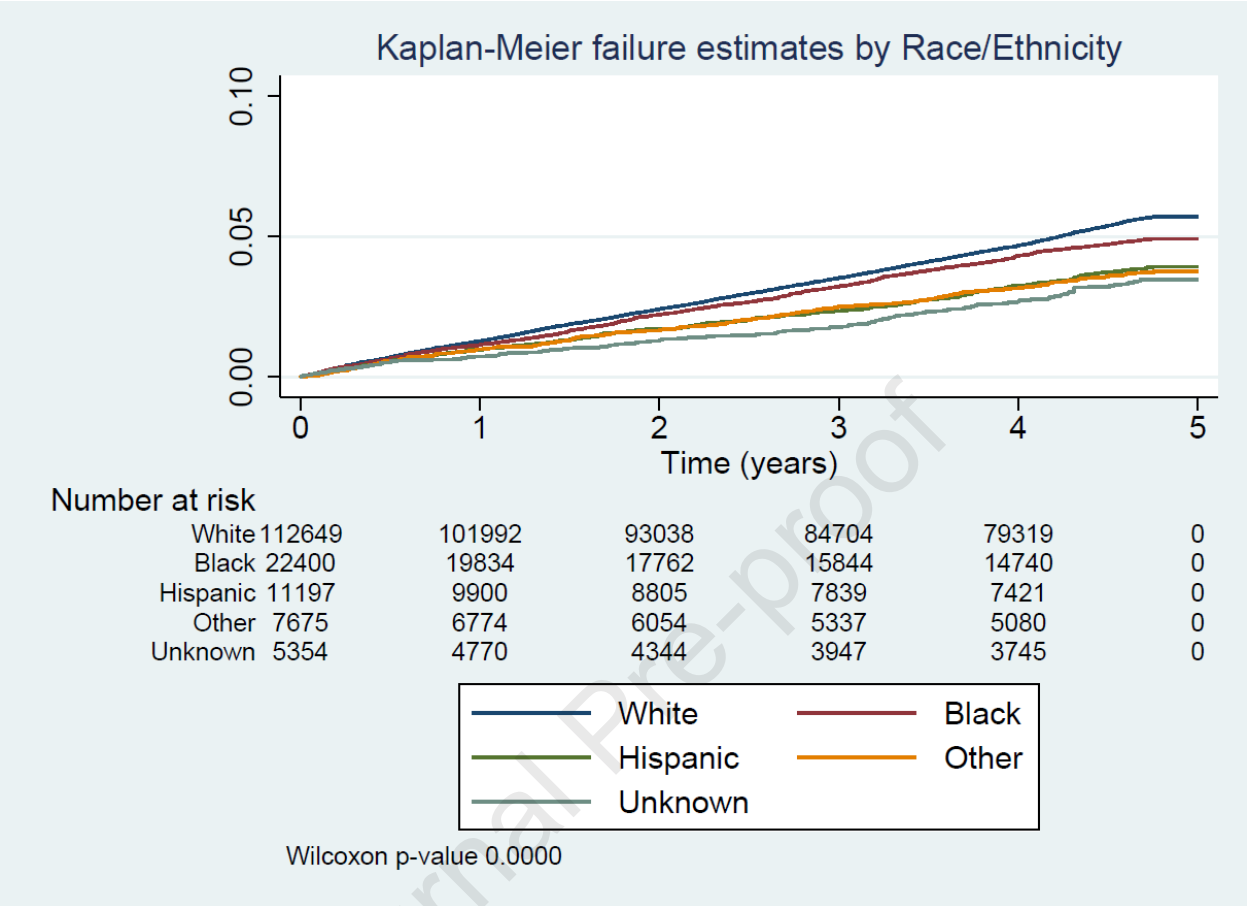

Declaration of interests

☒ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

☐ The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: