

Letters

RESEARCH LETTER

HEALTH CARE POLICY AND LAW

Antidiscrimination Laws and Kidney Transplant for Patients With Developmental Disabilities

People with intellectual and/or developmental disabilities (IDD) are less likely to receive organ transplants than peers without IDD,¹ partially because of disability-based discrimination. There is a growing national momentum to enact and enforce policies to improve equitable access to organ transplants for all patients, including those with IDD.^{2,3} Forty US states have laws prohibiting disability-based discrimination in the organ

transplant process (eTable 1 in Supplement 1). These laws differ in the inclusion of 2 specific strengthening provisions: (1) private right of action, which allows private individuals (instead of the government or other federal regulator) to file lawsuits in defense of their rights, and (2) expedited case review, which allows legal cases filed under these statutes to be heard by the court faster given the time-sensitive nature of transplant. We examined the extent to which antidiscrimination laws, and their associated provisions, mitigate disparities in rates of transplant evaluation and receipt for patients with end-stage kidney disease (ESKD) with IDD vs without IDD.

Methods | We analyzed the 2013-2023 Medicare Standard Analytical Files. Medicare insures qualifying US residents on

Table 1. Characteristics of the Matched Cohorts

Characteristic	Controls (n = 49 199)		Patients with IDD (n = 12 730)	
	No. (%)	Per 1000 PY	No. (%)	Per 1000 PY
Sex				
Male	30 404 (61.8)	122.2	7909 (62.1)	33.4
Female	18 794 (38.2)	76.4	4821 (37.9)	20.5
Race and ethnicity ^a				
Black	14 197 (28.9)	63.0	3578 (28.1)	16.4
Hispanic	1986 (4.0)	8.8	523 (4.1)	2.3
White	30 098 (61.2)	115.2	7870 (61.8)	32.1
Other ^b	2917 (5.9)	11.5	759 (6.0)	3.1
Age quartile at ESKD diagnosis				
Quartile 1: ≤40 y	13 005 (26.4)	54.7	3340 (26.2)	14.6
Quartile 2: 41-53 y	11 862 (24.1)	52.1	3394 (26.7)	16.2
Quartile 3: 54-64 y	11 540 (23.5)	46.9	3469 (27.3)	14.4
Quartile 4: ≥65 y	12 791 (26.0)	44.9	2527 (19.9)	8.7
Age at ESKD diagnosis, y				
<18	1539 (3.1)	4.2	445 (3.5)	5.5
≥18	47 659 (96.9)	194.4	12 285 (96.5)	247.0
US region				
Midwest	11 110 (22.6)	44.0	3255 (25.6)	13.6
Northeast	7653 (15.6)	30.8	2335 (18.3)	10.0
South	22 300 (45.3)	90.4	5311 (41.7)	22.3
West	8136 (16.5)	33.4	1829 (14.4)	8.0
Rurality				
Large metropolitan area: ≥1 000 000 population	24 671 (50.1)	100.9	6177 (48.5)	26.3
Small metropolitan area: <1 000 000 population	15 150 (30.8)	60.8	3936 (30.9)	16.8
Metropolitan area adjacent	5013 (10.2)	19.9	1455 (11.4)	6.0
Nonmetropolitan area: ≥2500 population	2021 (4.1)	8.0	611 (4.8)	2.6
Rural area: <2500 population	2344 (4.8)	9.1	551 (4.3)	2.3
State law present				
No law	5006 (10.2)	20.1	1323 (10.4)	5.7
Any law	44 192 (89.8)	178.5	11 407 (89.6)	48.2
Law provisions				
PRA	34 703 (70.5)	140.0	8983 (70.6)	38.1
ER	32 142 (65.3)	130.1	8322 (65.4)	35.5
PRA and ER	30 229 (61.4)	122.5	7750 (60.9)	33.0

Abbreviations: CCI, Charlson Comorbidity Index; CVD, cardiovascular disease; ER, expedited review; ESKD, end-stage kidney disease; IDD, intellectual and/or developmental disability; PRA, private right of action; PY, person-year.

^a Race and ethnicity were extracted from the Medicare Standard Analytical Files. These data were included in this analysis because the incidence of ESKD varies by race and ethnicity.

^b Other includes American Indian or Alaska Native, Asian/Native Hawaiian or Pacific Islander, multiple races, other not further specified, or unknown.

dialysis and kidney transplant recipients of any age. In accordance with 45 CFR §46.104, this cohort study was exempt from ethics review and informed consent due to use of limited datasets. We followed the [STROBE](#) reporting guideline.

We identified patients with ESKD with and without IDD (eTable 2 in [Supplement 1](#)) and performed propensity score matching on sex, race and ethnicity, law provisions, birth year, follow-up duration, comorbidities, frailty, estimated income, and distance to closest transplant center (eFigure in [Supplement 1](#)). We used staggered adoption difference-in-differences models to assess the implications of antidiscrimination laws on evaluation for and receipt of kidney transplants at the state level (eTable 3 in [Supplement 1](#)). We specified a negative binomial distribution with a log link, including a log offset for the number of patients within each state per month. We controlled for calendar month, year, and state-level covariates obtained from the US Census Bureau. We performed sensitivity analyses to assess the validity of our findings among the subset of patients who did not cross state lines for a transplant, among the subset of states with a state law change during the study period, and using single-stage and 2-stage regression models.

We conducted analyses in SAS v9.4 (SAS Institute Inc) and R 4.2.1⁴ (R Project for Statistical Computing). Significance was assessed at $P < .05$. The eMethods in [Supplement 1](#) provides additional details.

Results | The matched cohorts of patients with ESKD included 12 730 with IDD (7909 males [62.1%]) and 49 199 controls; 30 404 males [61.8%]). A total of 53 898 and 198 595 person-years, respectively, were observed ([Table 1](#)).

Overall, patients with IDD had lower rates of evaluation for a kidney transplant (incidence rate ratio [IRR], 0.78; 95% CI, 0.75-0.81) and receipt of a kidney transplant (IRR, 0.62; 95% CI, 0.57-0.66) than matched controls ([Table 2](#)). There was no significant association between passage of any law and disparities in evaluation or receipt rates. Among patients with IDD, there was no significant difference in rates of transplant evaluation or receipt as a function of laws containing expedited review and/or private right of action. All sensitivity analyses resulted in findings similar to those of primary analyses.

Discussion | This study adds to a national discourse about the need for transparency and equal access to organ transplant for all, including people with IDD and other populations. While antidiscrimination laws are important in advancing equity for patients with ESKD and IDD, these laws are not associated with more equitable rates of evaluation or receipt of kidney transplant.

Our findings may reflect challenges in translating legal protections into clinical practice changes. Discriminatory treatment can be difficult to identify and prove, even when legal protections exist. Awareness of protections and resources to challenge potential discrimination may vary among people with IDD and their families. Consequently, legislation alone may be insufficient to eliminate disparities without complementary efforts to improve transparency, accountability, and oversight.

Table 2. Analysis Results of Kidney Transplant Evaluation and Receipt of Transplant as a Function of Any Law Enactment and the Presence of Strengthening Provisions

	IRR (95% CI)	
	Evaluation for kidney transplant	Receipt of kidney transplant
Any law enactment		
IDD vs control		
Overall	0.78 (0.75-0.81) ^a	0.62 (0.57-0.66) ^a
No law present	0.78 (0.74-0.83) ^a	0.61 (0.57-0.65) ^a
Any law present	0.77 (0.73-0.81) ^a	0.62 (0.55-0.70) ^a
IDD specific		
Any law vs no law	0.94 (0.86-1.04)	0.98 (0.84-1.14)
Control specific		
Any law vs no law	0.96 (0.88-1.05)	0.96 (0.86-1.08)
Strengthening provisions		
IDD vs control		
Overall	0.79 (0.77-0.82) ^a	0.64 (0.60-0.69) ^a
PRA	0.74 (0.70-0.79) ^a	0.65 (0.57-0.75) ^a
ER	0.82 (0.79-0.85) ^a	0.62 (0.58-0.66) ^a
PRA and ER	0.75 (0.70-0.80) ^a	0.58 (0.51-0.67) ^a
IDD specific		
PRA present vs absent	1.01 (0.91-1.12)	0.92 (0.78-1.09)
ER present vs absent	1.00 (0.91-1.11)	1.08 (0.90-1.28)
PRA and ER present vs both absent	1.01 (0.93-1.10)	0.99 (0.82-1.20)
Control specific		
PRA present vs absent	1.14 (1.04-1.25) ^b	0.90 (0.77-1.05)
ER present vs absent	0.94 (0.86-1.02)	1.17 (1.01-1.35) ^b
PRA and ER present vs both absent	1.07 (1.00-1.15)	1.05 (0.97-1.13)

Abbreviations: ER, expedited review; IDD, intellectual and/or developmental disability; PRA, private right of action; IRR, incidence rate ratio.

^a $P < .001$.

^b Statistically significant.

Proposed strategies to mitigate disparities for other marginalized populations may also be beneficial for people with IDD.^{5,6} For example, electronic health record-based registries may be able to systematically identify and automatically refer eligible candidates for evaluation to circumvent potential physician biases at the referral stage.⁶ Improving transparency in the transplant committee selection process by allowing patient or advocate participation has also been posited as a solution.⁵ Finally, there is a need for data registries to monitor candidates' progress through the transplant care pathway by social determinants of health to identify systemic and structural barriers to transplant access.

Limitations include a lack of measures of transplant appropriateness or social support. We could not ascertain whether patients chose not to pursue evaluation or transplant but could have. Other limitations were related to cohort identification, data capture, and measurement of transplant access.

Advocacy efforts that strengthen antidiscrimination legislation, reduce clinician implicit bias, and mandate transparency in transplant center decision-making are needed to create equitable access to this lifesaving therapy for kidney

transplant candidates with IDD. Ensuring equitable access to organ transplant requires that people with IDD are holistically evaluated for eligibility without IDD-specific contraindications or bias.

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