

Inequities in Receipt of the North Carolina Medicaid Waiver Among Individuals with Intellectual Disability or Autism Spectrum Disorder

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ABSTRACT: *Objective:* We examined characteristics associated with receiving the North Carolina Home and Community-Based Services Waiver for intellectual and developmental disabilities (I/DDs) and its association with emergency department (ED) utilization. *Method:* Through analysis of the North Carolina 2017 to 2018 Medicaid claims and enrollment data, we examined characteristics (age, sex, race and ethnicity, geography, diagnosis (intellectual disability [ID] with or without autism spectrum disorders or autism spectrum disorder without ID) associated with receiving the NC I/DD Waiver and the association of this Waiver with ED utilization. We identified patients with at least 1 International Classification of Diseases-10-CM diagnosis code for an ID or autism spectrum disorder. We excluded patients with missing county information and whose enrollment in the NC I/DD Waiver program began after October 1, 2017. *Results:* Only 22% of 53,531 individuals with I/DD in North Carolina received the Waiver. Non-Hispanic Blacks and Hispanic individuals were less likely to receive the Waiver than non-Hispanic White individuals. Adults (>21 years old), men, and urban residents were more likely to receive the Waiver. Individuals who received the Waiver were 31% less likely to use the ED. *Conclusion:* Innovative strategies are needed to provide equitable access to the NC I/DD Waiver and provide services to the 14,000 people with I/DD currently waiting to receive the Waiver. Through the Waiver, those with I/DD can access preventative and therapeutic outpatient services and decrease their need for ED care. These findings highlight the need for policy reform to address inequities in access to the Waiver for individuals with I/DD.

(*J Dev Behav Pediatr* 43:393–401, 2022) **Index terms:** intellectual disabilities, developmental disabilities, home and community-based services waivers, Medicaid, health disparities.

People with intellectual and developmental disabilities (I/DDs; e.g., autism spectrum disorder and Down syn-

drome) experience significant health care disparities, such as differences in health insurance coverage, quality of care, and access to and utilization of care when compared with those without I/DDs.^{1–6} Furthermore, compared with the non-I/DD population, mortality rates among adults with I/DD are markedly elevated, with over a third of deaths being potentially preventable with health care intervention (e.g., pneumonia).⁷ Health disparities based on disability status are amplified for individuals with I/DD from racial and ethnic minority groups, socioeconomically disadvantaged populations, and those residing in rural settings.^{8–10} For example, Black and LatinX adults with I/DDs have markedly poorer health outcomes than same-race and ethnic peers without I/DDs and White adults with and without I/DDs.⁹ Disparities in care and services have been attributed to (1) the lack of educational preparation and experience of health care providers; (2) stigmatization, discrimination, and segregation toward people with I/DD; and (3) institutional and cultural racism toward individuals who are also from racial and ethnic minority groups.^{9,11,12}

Previously, particularly before the 1960s, people with I/DD often lived in institutions and segregated from their families and communities. However, through federal

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legislation passed in 1981, Medicaid Home and Community-Based Services (HCBS) 1915 (c) waivers were enacted to “waive” certain Social Security Act provisions, such as income eligibility criteria, and to enable states to create customized programs to address the needs of particular underserved populations who are at high risk for institutional-based care.^{13,14} The federal Medicaid HCBS waivers for I/DD (HCBS I/DD waivers) are the largest source of funding for long-term supports and services for people with I/DD within the United States.¹³ HCBS I/DD waivers changed the national landscape from facility-based to family home-based and community-based services and supports for individuals with I/DD.¹³ Receipt of these waivers can reduce segregation and increase the likelihood that people with I/DD receive meaningful community opportunities as required by the Centers for Medicare and Medicaid Services.^{13,15}

Benefits of HCBS waivers have been identified; however, there is large variability in how HCBS waivers are designed and administered across states, which further complicates evaluating their effectiveness for recipients with I/DD.^{16–18} Leslie and colleagues^{17,18} demonstrated that unmet needs for children with autism spectrum disorder (ASD) were significantly decreased with the use of HCBS waivers. Furthermore, Eskow et al. found Maryland HCBS waiver recipients with ASD had improved family quality of life and independent living skills over the course of a year compared with those on the waiver waitlist.

Each state’s HCBS waiver program must be cost-neutral: that is, costs of the waiver program cannot exceed costs that would be incurred if the state did not have the waiver.¹⁶ To achieve this cost-neutrality, states commonly use cost containment measures (e.g., waiting lists and individual cost limits).^{16,20} Previous analyses have demonstrated large variability across states and the services they provide, revealing vast differences in total participants, average spending per participant, and total spending.^{13,21} Friedman¹³ found the HCBS I/DD waivers served an average of 12,784 participants a year per state and 563,116 unduplicated participants per year total in the United States. Regarding costs, the average state projected spending was \$606.7 million per year, with a national total of \$26.9 billion projected per year.¹³ At the individual level, the average spending per participant was \$49,002.¹³

The North Carolina (NC) HCBS Waiver for I/DD (NC I/DD Waiver) is also referred to as the NC Innovations Waiver. In a recent analysis of the scope of coverage and variability in states’ coverage of children with medical complexity, with 1 being the highest coverage and 46 being the lowest coverage, NC was ranked 36.¹⁶ In NC, open waiver slots occur infrequently because this only happens if the state creates more slots or the recipient moves, dies, or voluntarily leaves the program. Although nationally the average waiting time exceeds 2 years,²⁰ the NC I/DD Waiver waitlist is 7 to 10 years,²² indicating that the need for these services far exceeds the currently available resources in NC.

The national landscape of HCBS I/DD waivers is complex, and how they may address or contribute to health disparities is not currently known. It is important to examine the distribution of this scarce resource to determine whether there are disparities by race, ethnicity, age, sex, or geography (rural or urban county). It is also important to examine the degree to which this type of benefit can affect the salient aspects of health services utilization, such as reduction in emergency department (ED) utilization. Intellectual disability (ID) and ASD are the 2 most common I/DD diagnoses for the NC I/DD Waiver, given a key eligibility criterion is meeting the requirements for Intermediate Care Facility for Individuals with Intellectual Disabilities level of care. In addition, individuals with ASD without ID may have different comorbid conditions and utilization of mental health services. These differences may be predictors for NC I/DD Waiver receipt and ED utilization. To address this gap in the current understanding of the HCBS I/DD waivers, we conducted this study to examine (1) the characteristics of NC Medicaid recipients with I/DD by receipt of the NC I/DD Waiver; (2) the effect of age, sex, race and ethnicity, and geography on receipt of the NC I/DD Waiver; and (3) the effect of having the NC I/DD Waiver on ED utilization.

METHODS

Data Sources

We analyzed North Carolina (NC) Medicaid 2017 to 2018 claims and enrollment data obtained from the NC Department of Health and Human Services (DHHS) through an agreement with Duke University Department of Population Health Sciences. Briefly, the enrollment file contains demographic and programmatic information for each Medicaid beneficiary, including date of birth, sex, race, ethnicity, county of residence, and benefit specific enrollment dates. We used institutional and professional claims files to identify diagnoses and services used by patients. The institutional file contains services billed to and paid for by the Medicaid program for hospitalizations, skilled nursing facility stays, mental health stays, and other outpatient services provided by a facility. The professional file contains claims paid for by the Medicaid program for services delivered by providers, such as physicians, personal care services, and behavioral health practitioners. Both the institutional and professional claims include dates of services, diagnoses, procedures, and provider information, such as the National Provider Identifier. This study was approved by the Duke University Health System Institutional Review Board and the NC DHHS.

Study Population

We used 2017 to 2018 NC Medicaid claims to identify patients with at least 1 International Classification of Diseases (ICD)-10-CM diagnosis code for an intellectual disability (ID) or autism spectrum disorder (ASD) using institutional and professional claims data for encounters that occurred from October 1, 2017, through September

30, 2018 (Appendix Table 1, Supplemental Digital Content 1, <http://links.lww.com/JDBP/A354>). Using the enrollment file, we excluded patients with missing county information and patients whose enrollment in the NC intellectual and developmental disabilities (I/DD) Waiver program began after October 1, 2017.

Study Variables

We categorized age as follows: 0 to 17, 18 to 21, and older than 21 years. We chose these age ranges as they are conceptually meaningful both developmentally (child, young adulthood, and adulthood) and legally (at age 18 years, one is considered an adult and may require legal guardianship). We recognized that children are underrepresented on the NC I/DD Waiver given the waiting list and thus wanted to examine this impact specifically. Finally, we included individuals age 18 to 21 years as a separate group, given that this is a priority population that is navigating simultaneous changes (e.g., exiting from high school and transitioning to adult-based services), which can affect service needs and utilization. We combined race and ethnicity variables into a single categorical variable: non-Hispanic White, Hispanic White, non-Hispanic Black, Hispanic Black, and other race/ethnicity. Counties were classified as either urban or rural according to the NC Office of State Budget and Management. We classified patients according to whether they had (1) ID with or without ASD or (2) ASD without ID and identified comorbid behavioral health conditions using ICD-10 codes (Appendix Supplemental Table 2, Supplemental Digital Content 1, <http://links.lww.com/JDBP/A354>). Next, we identified whether a patient had at least 1 claim in the institutional or professional claims files at any point in the study period for a range of mental health services (Appendix Supplemental Table 3, Supplemental Digital Content 1, <http://links.lww.com/JDBP/A354>). The mental health services, detailed by their corresponding treatment Common Procedural Terminology (CPT) codes, are organized into the following code categories: screening, treatment/intervention, I/DD-related services, NC I/DD Waiver services, applied behavior analysis, and physical/occupational/speech therapy. These CPT codes are mutually exclusive. However, the nature of some of these services is similar [e.g., respite care (S5150) is listed under NC I/DD Waiver services, and respite (H0045) is listed under I/DD-related services]. NC I/DD Waiver services are tailored to the persons' needs based on their Individual Support Plan and may include crisis services, day supports, assistive technology, community navigation, community networking, community transition, community living and support, financial support services, supported employment, home and vehicle modifications, natural supports education, residential supports, supported living, specialized consultation services (e.g., psychology, physical therapy, and occupational therapy beyond standard Medicaid service limits), and respite for caregivers.²³ The mental health services CPT codes provided within the NC I/DD Waiver services are included in Appendix Supplemental Table 3, Supplemental Digital Content 1, <http://links.lww.com/JDBP/A354>. NC I/DD Waiver services are provided to people with current

waiver slots. However, through Medicaid 1915(b) (3) services and other waivers and programs, some of these services (e.g., respite and supported employment) are available to people who are eligible for Medicaid based on medical necessity but do not yet have a NC I/DD Waiver slot. I/DD-related services include important mental health services, including Assertive Community Treatment Team, psychosocial rehabilitation, and respite, and may be available to those who have a NC I/DD Waiver slot and those who do not.

Outcomes

Outcomes of interest for this study were receipt of the NC I/DD Waiver and any outpatient ED visit. We used the enrollment file to identify Medicaid beneficiaries with ID or ASD diagnosis who were enrolled in the NC I/DD Waiver program. We used CPT and revenue codes found on a single institutional or professional claim to identify any ED use during the study period (Appendix Supplemental Table 4, Supplemental Digital Content 1, <http://links.lww.com/JDBP/A354>).

Statistical Analysis

We describe baseline characteristics of the population receiving the NC I/DD Waiver benefit with frequencies and percentages for categorical variables and means with standard deviations for continuous variables. Differences between patients receiving the NC I/DD Waiver or not were tested using χ^2 tests for categorical variables and Wilcoxon rank sum tests for continuous variables.

We fitted unadjusted and multivariable-adjusted log-binomial models to examine factors associated with the likelihood of receipt of the NC I/DD Waiver benefit. We chose our reference categories based on their being more common in the study population (e.g., older than 21 years and male). The unadjusted model includes the single independent variable and random intercept for patient's county of residence. In the multivariable model, we included covariates for age, sex, race and ethnicity, mental health diagnosis, and rural/urban county location and additionally included a random intercept for the patient's county of residence to estimate geographic variation in IW receipt. Similarly, we fitted unadjusted and multivariable log-binomial models to examine factors associated with the risk of any ED use in the study period, including those same covariates and a variable for receipt of the NC I/DD Waiver benefit. We used a 2-tailed $\alpha = 0.05$ to establish statistical significance and report 95% confidence intervals. All analyses were performed using SAS 9.4 Cary, NC.

RESULTS

After applying all eligibility criteria, there were 53,531 NC Medicaid patients with intellectual disability (ID) or autism spectrum disorder (ASD) diagnosis in the study period. The average age (SD) of the overall cohort was 27.2 (19.7) years, over two-thirds were male (67.0%), and more than half were Non-Hispanic White (51.3%). ID was more common than ASD (58.6% vs.

Table 1. Characteristics of NC Medicaid Patients with Intellectual Disabilities or Autism Spectrum Disorder Overall and by Receipt of the NC I/DD Waiver^{a,b,c}

	Overall, N (%)	No Waiver, N (%)	Received Waiver, N (%)	<i>p</i>
N	53,531	41,563	11,968	
Demographics				
Age 0–17 years	22,531 (42.1)	21,079 (50.7)	1452 (12.1)	<0.001
Age 18–21 years	4503 (8.4)	3020 (7.3)	1483 (12.4)	<0.001
Age >21 years	26,497 (49.5)	17,464 (42.0)	9033 (75.5)	<0.001
Male sex	35,852 (67.0)	28,306 (68.1)	7546 (63.1)	<0.001
Non-Hispanic White	27,447 (51.3)	20,669 (49.7)	6778 (56.6)	<0.001
Hispanic White	3042 (5.7)	2810 (6.8)	232 (1.9)	<0.001
Non-Hispanic Black	16,019 (29.9)	12,512 (30.1)	3507 (29.3)	0.09
Hispanic Black	217 (0.4)	192 (0.5)	25 (0.2)	<0.001
Other race/ethnicity	6806 (12.7)	5380 (12.9)	1426 (11.9)	0.003
I/DD				
Intellectual disabilities, with or without autism spectrum disorder	31,378 (58.6)	20,735 (49.9)	10,643 (88.9)	<0.001
Autism spectrum disorder without intellectual disabilities	22,153 (41.4)	20,828 (50.1)	1325 (11.1)	<0.001
MH services				
Any MH service ^d	45,026 (84.1)	33,079 (79.6)	11,947 (99.8)	<0.001
Screening	10,919 (20.4)	10,134 (24.4)	785 (6.6)	<0.001
Treatment/intervention	25,674 (48.0)	20,338 (48.9)	5336 (44.6)	<0.001
I/DD-related services	10,396 (19.4)	6793 (16.3)	3603 (30.1)	<0.001
NC I/DD Waiver services	18,337 (34.3)	6435 (15.5)	11,902 (99.4)	<0.001
Applied behavior analysis	562 (1.0)	516 (1.2)	46 (0.4)	<0.001
Physical/occupational/speech therapy	17,328 (32.4)	15,503 (37.3)	1825 (15.2)	<0.001
Emergency department visit	18,832 (35.2)	15,593 (37.5)	3239 (27.1)	<0.001
Comorbid MH conditions				
Any other condition ^e	30,237 (56.5)	24,811 (59.7)	5426 (45.3)	<0.001
Attention-deficit/hyperactivity disorder	13,692 (25.6)	12,493 (30.1)	1199 (10.0)	<0.001
Schizophrenia spectrum and other psychotic disorders	5804 (10.8)	4448 (10.7)	1356 (11.3)	0.05
Bipolar and related disorders	4093 (7.6)	3212 (7.7)	881 (7.4)	0.18
Depressive disorders	9398 (17.6)	7694 (18.5)	1704 (14.2)	<0.001
Disruptive mood dysregulation disorder	1453 (2.7)	1329 (3.2)	124 (1.0)	<0.001
Anxiety disorders and obsessive-compulsive and related disorders	11,508 (21.5)	9307 (22.4)	2201 (18.4)	<0.001
Trauma- and stress-related disorders	2625 (4.9)	2331 (5.6)	294 (2.5)	<0.001
Somatic symptom and related disorders	371 (0.7)	310 (0.7)	61 (0.5)	0.006
Feeding and eating disorders	461 (0.9)	392 (0.9)	69 (0.6)	<0.001
Disruptive, impulsive-control, and conduct disorders	6554 (12.2)	5483 (13.2)	1071 (8.9)	<0.001
Substance-related and addictive disorders	1700 (3.2)	1538 (3.7)	162 (1.4)	<0.001
Adjustment disorder	2468 (4.6)	2199 (5.3)	269 (2.2)	<0.001
Geographies				
Urban	39,572 (73.9)	30,646 (73.7)	8926 (74.6)	0.06
Rural	13,959 (26.1)	10,917 (26.3)	3042 (25.4)	0.06

^aHypothesis testing between patients who received the NC I/DD Waiver vs. those who did not. ^bCategorical variables are presented as frequencies with percentages. ^cCell sizes <11 have been suppressed. ^dAny MH service includes all services listed under the "MH Services" heading. ^eAny other condition includes all the conditions listed under the "Comorbid Mental Health Conditions" heading. I/DD, intellectual/developmental disabilities; MH, mental health.

41.4%) (Table 1). Just over one-fifth of the cohort received the North Carolina (NC) intellectual and developmental disabilities (I/DD) Waiver, with significant differences in age, sex, and race and ethnicity between patients who received the NC I/DD Waiver benefit compared with

those without the benefit (Table 1). For example, the mean (SD) of age among those who had the NC I/DD Waiver benefit was 32.8 (14.5) years compared with 25.6 (20.7) years for those without the benefit (results not shown). Of the patients receiving the I/DD Waiver, 89%

had ID and essentially all received at least 1 mental health service including NC I/DD Waiver services (99%) and I/DD-related services (30%). Of the patients without the I/DD Waiver, there were fewer who received at least 1 mental health service (80%), including NC I/DD Waiver services (16%) and I/DD-related services (16%).

Unadjusted and multivariable-adjusted associations between patient characteristics and receipt of NC I/DD Waiver are presented in Table 2. There were differences in the likelihood of having this benefit for children (aged 0–17 years) compared with adults older than 21 years in both unadjusted and adjusted models. In the adjusted model, children were 61% less likely to have the NC I/DD Waiver benefit than those older than 21 years [adjusted Risk Ratio [RR] = 0.39, 95% confidence interval [CI]: (0.37, 0.41)]. Similarly, women had 12% lower likelihood of having this benefit compared with men (adjusted RR = 0.88, 95% CI: [0.86, 0.91]). All race-ethnicity combinations had a lower likelihood of receiving the NC I/DD Waiver benefit compared with non-Hispanic Whites including 37% lower for Hispanic Whites and 15% lower for non-Hispanic Blacks (Table 2).

After multivariable adjustment, the likelihood of receiving the NC I/DD Waiver was 9% lower among those who lived in a rural county compared with those in an urban county [RR = 0.91, 95% CI: (0.84, 0.98)]. There were also statistically significant differences in likelihood of NC I/DD Waiver receipt across counties (G-side random effects test $p < 0.0001$). For example, the likelihood of Waiver receipt in Wake county was 24% higher than state average compared with 26% lower in adjacent Johnston County (Supplemental Table 1, Supplemental Digital Content 1, <http://links.lww.com/JDBP/A354>). There was variation across the state in the observed proportion of I/DD patients with the Waiver benefit with a minimum of 4% and maximum of 37% (Fig. 1).

Finally, we report unadjusted and multivariable-adjusted model estimates for any ED use in the study period (Table 3). In the unadjusted and adjusted models, we found a statistically significant association between receipt of NC I/DD Waiver and ED utilization in this study population of patients with I/DD. In the adjusted

model, individuals who received the NC I/DD Waiver benefit were 31% less likely to use the ED compared with patients without [adjusted RR = 0.69, 95% CI: (0.66, 0.71)]. In a sensitivity analysis excluding dual Medicare-Medicaid eligible beneficiaries, we found no difference in the adjusted model estimates (results not shown).

DISCUSSION

This study examined (1) the characteristics of North Carolina (NC) Medicaid patients with intellectual and developmental disabilities (I/DDs) by receipt of the NC I/DD Waiver; (2) the effect of age, sex, race and ethnicity, and geography on receipt of the NC I/DD Waiver benefit; and (3) the effect of having the NC I/DD Waiver on ED utilization. We identified concerning disparities across age, sex, race and ethnicity, and geographic location between NC Medicaid patients with and without an NC I/DD Waiver. Non-Hispanic Whites as compared with non-Hispanic Blacks or Hispanic individuals were significantly more likely to receive the NC I/DD Waiver. Adults (>21 years old), men, and urban residents were also more likely to receive the NC I/DD Waiver. In addition, there was a statistically significant protective association between receipt of the NC I/DD Waiver and lower likelihood of emergency department (ED) utilization.

All I/DDs arise in childhood, and with the increasing prevalence rates of autism spectrum disorder (ASD),²⁴ ID, and other developmental disabilities⁸ over the past decade (improved child survival rates, improvements in developmental screening, and improved access to diagnostic and treatment services²⁵), the demands for I/DD services are increasing. It is important for health care providers and policymakers to understand the landscape as children get older and help them access services if Waiver slots are not available.²⁶

Individuals of Racial and Ethnic Minority Groups Less Likely to Receive the North Carolina Intellectual and Developmental Disabilities Waiver

The role of race and ethnicity in accessing and receiving I/DD services is important and cannot be overstated. Racial and ethnic minority patients were significantly less likely to

Table 2. Unadjusted and Multivariable-Adjusted Associations Between Patient Characteristics and Receipt of the NC I/DD Waiver^c

Variable	Unadjusted Risk Ratio (95% CI)	<i>p</i>	Adjusted Risk Ratio (95% CI)	<i>p</i>
Age 0–17 vs. >21 years	0.19 (0.18, 0.20)	<0.0001	0.39 (0.37, 0.41)	<0.0001
Age 18–21 vs. >21 years	0.95 (0.91, 1.00)	0.0413	1.24 (1.19, 1.29)	<0.0001
ID vs. ASD	5.72 (5.42, 6.04)	<0.0001	3.40 (3.20, 3.61)	<0.0001
Women vs. men	1.19 (1.15, 1.23)	<0.0001	0.88 (0.86, 0.91)	<0.0001
Hispanic White vs. NHW	0.30 (0.26, 0.34)	<0.0001	0.63 (0.56, 0.71)	<0.0001
Non-Hispanic Black vs. NHW	0.88 (0.85, 0.91)	<0.0001	0.85 (0.83, 0.88)	<0.0001
Hispanic Black vs. NHW	0.44 (0.30, 0.64)	<0.0001	0.74 (0.53, 1.03)	0.0765
Other race/ethnicity vs. NHW	0.84 (0.80, 0.88)	<0.0001	0.80 (0.76, 0.83)	<0.0001
Rural vs. urban	0.97 (0.89, 1.05)	0.4775	0.91 (0.84, 0.98)	0.0172

ASD, autism spectrum disorder; CI, confidence interval; ID, intellectual disability; NHW, non-Hispanic White. ^aAll models include patient's county of residence as a random intercept; adjusted risk ratio models are adjusted for all variables in the left column. I/DD, intellectual/developmental disabilities.

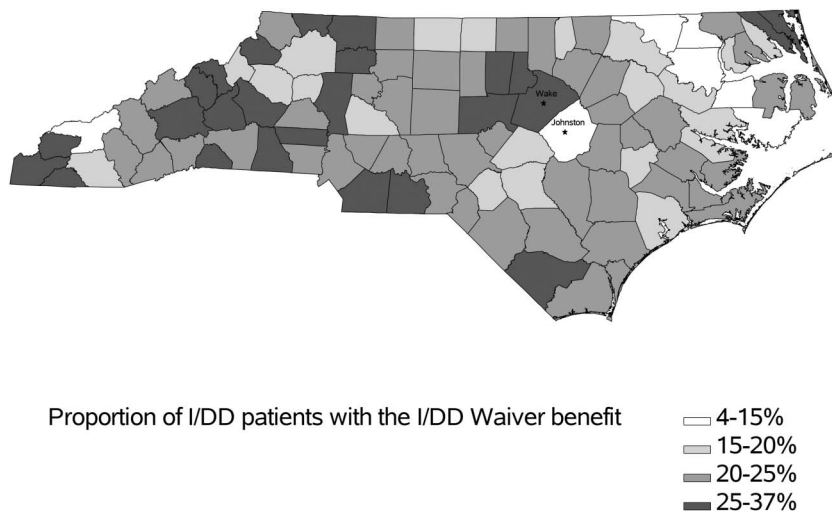


Figure 1. Variation in receipt of NC I/DD Waiver benefit by county. I/DD, intellectual/developmental disabilities.

have access to this valuable benefit. The potential root causes of these disparities were not examined in this study. However, previous research has indicated that health care disparities may be perpetuated by stigmatizing attitudes,¹² structural racism,²⁷ and inequalities resulting in lower access to quality health care¹⁻⁵ and inferior health outcomes.^{2,3,28} For example, LaClair and colleagues²⁹ studied the effect of Medicaid waivers on ameliorating racial and ethnic disparities among children with ASD and called for research to better understand the barriers to accessing the Home and Community-Based Services (HCBS) I/DD waivers and the way in which the structures of these waivers may affect people with I/DD who are from racial and ethnic minority groups.

Individuals in Rural Counties Less Likely to Receive the North Carolina Intellectual and Developmental Disabilities Waiver

The geographic location of patients is also associated with the receipt of NC I/DD Waiver services, with rural

residents having 9% decreased likelihood of receiving the NC I/DD Waiver compared with those living in urban counties. One illustrative example is to look at 2 adjacent counties in which patients in Wake County (urban) had 24% higher likelihood of having the NC I/DD Waiver compared with the mean and patients in Johnston County (rural) had 26% lower likelihood compared with the mean. NC I/DD Waiver slots are distributed based on county population, and it is not clear why some counties have more individuals with I/DD connected to the Waiver. One hypothesis is that individuals in rural areas may have less access to information about services such as the NC I/DD Waiver.

There is risk that due to bias and lack of knowledge of the process, health care providers and other key community supports may risk inequitably helping families navigate this process. This is particularly important, given that the NC I/DD Waiver waiting list, known as the *Registry of Unmet Needs*, currently functions as a first-come, first-served list (although it was a needs-

Table 3. Unadjusted and Multivariable-Adjusted Associations Between Receipt of NC I/DD Waiver, Patient Characteristics, and Risk of Emergency Department Utilization

Variable	Unadjusted Risk Ratio (95% CI)	p	Adjusted Risk Ratio (95% CI)	p
NC I/DD Waiver yes vs. no	0.73 (0.70, 0.75)	<0.0001	0.69 (0.66, 0.71)	<0.0001
Age 0–17 vs. >21 years	1.03 (1.00, 1.05)	0.0298	1.10 (1.06, 1.13)	<0.0001
Age 18–21 vs. >21 years	0.95 (0.91, 0.99)	0.0221	1.03 (0.99, 1.08)	0.1841
ID vs. ASD ^a	1.11 (1.08, 1.13)	<0.0001	1.26 (1.22, 1.30)	<0.0001
Women vs. man	1.08 (1.06, 1.11)	<0.0001	1.05 (1.03, 1.08)	<0.0001
Hispanic White vs. NHW ^b	1.00 (0.95, 1.06)	0.9022	0.97 (0.92, 1.02)	0.2035
Non-Hispanic Black vs. NHW	1.09 (1.06, 1.12)	<0.0001	1.06 (1.03, 1.08)	<0.0001
Hispanic Black vs. NHW	0.95 (0.79, 1.16)	0.6356	0.91 (0.75, 1.11)	0.3622
Other race/ethnicity vs. NHW	0.99 (0.95, 1.02)	0.4817	0.97 (0.93, 1.01)	0.0905
Rural vs. urban	1.05 (1.00, 1.10)	0.0460	1.03 (0.99, 1.08)	0.1451

All models include patient's county of residence as a random intercept; adjusted risk ratio models are adjusted for all variables in the left column. ^aID, intellectual disability; ASD, autism spectrum disorder. ^bNHW, non-Hispanic White. I/DD, intellectual/developmental disabilities.

based program until 2013). Furthermore, in recent analyses of 47 reporting states, NC had the ninth largest waiting list in the United States.³⁰ As of Spring 2020, there were 14,000 North Carolinians on the waiting list, with at least 250 waiting for 10 years and some having waited as long as 17 years.^{31,32} Efforts are being made to address this wait that include 1000 NC I/DD Waiver slots newly funded through Session 2021 budget appropriations.

Individuals Younger Than 18 Years Less Likely to Receive the North Carolina Intellectual and Developmental Disabilities Waiver

We found differences across age groups in likelihood of receiving the NC I/DD Waiver. Children younger than 18 years had 61% lower likelihood of receiving the NC I/DD Waiver than adults older than 21 years. This finding is particularly problematic because this waiver is less accessible to children because of the high demand for limited slots and the length of time on the waiting list. Given evidence that intervention earlier in childhood can improve adult outcomes,^{33,34} long delays in accessing the waiver (i.e., being added to the waiver waiting list later in childhood) may affect the health trajectories and functional adult outcomes of NC youth (e.g., general health status, employment, and independent living).

Risk of Emergency Department Utilization Lower Among North Carolina Intellectual and Developmental Disabilities Waiver Recipients

Health care disparities are perpetuated by inequalities resulting in inferior health outcomes, including higher rates of hospitalization and use of acute care services.^{2,3,28} Fewer ED visits are indicative of better health and preventative care, increased quality of life, and increased utilization of community-based health services.^{35,36} A noteworthy positive finding from this study is the 31% reduction in the risk of ED use among those with the NC I/DD Waiver benefit compared with patients without the benefit. Friedman³⁶ found that adults with I/DD have an average of 1 ED visit per year, and those with complex medical support needs and/or behavioral support needs had dramatically increased ED utilization. In addition, those living in family homes had a 52% decrease in ED visits compared with those living in provider owned-homes or operated-homes.³⁶ Our finding that more patients receiving the NC I/DD Waiver benefit receive mental health services, including NC I/DD Waiver services and I/DD-related services, suggests that these services likely contribute to the lower risk of ED utilization. Previous studies have shown that access to outpatient psychiatric services³⁷ and I/DD Waiver services is strongly associated with reduced ED visits, although specific causal pathways are not known.³⁸ One of the goals of the HCBS Waiver is to keep individuals with I/DD with their family in the community, which is

also an important outcome to be considered in the future.

Limitations

The limitations of this study include that there may be lack of generalizability because findings in this analysis are specific to a population of Medicaid patients with I/DD in a single state. We also only examined claims for a 12-month period and did not require continuous Medicaid enrollment, which could affect our estimates. The goal of this study was to describe the distribution of I/DD and the NC I/DD Waiver independent of continuous enrollment. Although patients may have been misclassified as having an I/DD because we only required 1 claim with a qualifying ICD-10 diagnosis code, we chose to be less restrictive because this is the first analysis of its kind within the NC Medicaid claims data. We assigned a patient to their geography (i.e., county and rural status) according to their latest residential county in the study period, which may differ from the county in which they received treatment. In addition, if a patient received the Waiver in one county, then moved, the Waiver slot moved with the individual. Finally, the purpose of this analysis was not to evaluate causality, but rather to describe a population of I/DD patients with and without the NC I/DD Waiver benefit and to quantify how that benefit is received and affects ED utilization.

Practice, Policy, and Research Implications

HCBS waivers broadly, and the NC I/DD Waiver specifically, have significant benefits and are quite valuable to individuals with I/DD and their families. For example, in one study, caregivers of those receiving the HCBS I/DD Waiver had improvement in caregiver-perceived outcomes.³⁹ Harrington and colleagues⁴⁰ found that HCBS waivers resulted in significant cost savings for Medicaid long-term care programs including an estimated \$57,338 saved per waiver recipient compared with the costs of Medicaid institutional care. It is important to ensure health care providers, payers, educational stakeholders, and other key community supports are knowledgeable about HCBS I/DD waivers and can guide people with I/DD and their families around strategies for accessing I/DD waivers. HCBS I/DD waivers need to be tailored for the recipient's needs and use a family-centered approach.¹⁶ Recognizing and removing cultural and practical barriers to this cumbersome process is needed to ensure efficient and equitable access to HCBS I/DD waivers.

As prevalence rates for some I/DD conditions continue to increase, there are potentially serious implications for individuals with I/DD and NC if the NC I/DD Waiver waitlist continues to grow over time. A strength of the NC I/DD Waiver is that it is available to people with I/DD across the life span. Waivers that cover both children and adults are valuable because they are designed with recognition of critical periods of

development and prevent gaps in services at crucial times, such as when the recipient is transitioning to adulthood. However, serving children and adults on the same waiver also presents challenges of meeting different child and family-based needs within the same waiver¹⁶ and availability of waiver spots for children. Including all ages on the same waiver contributes to long waiting lists. Currently, only one-fifth of individuals with I/DD in NC have an NC I/DD Waiver, and the percentage of those without an NC I/DD Waiver will likely rise in the future. Without an NC I/DD Waiver, specific services necessary to help individuals with I/DDs remain in the community are not covered, thus increasing the probability of institutionalized care and worse health outcomes. Increased wait times for the NC I/DD Waiver may not only have substantial consequences for individuals with I/DD and their families, but it could also have a significant financial impact on the state's government spending.

HCBS waiting lists are a significant concern for individuals with I/DD on a national level as well, with average wait of approximately 66 months for a HCBS waiver.⁴¹ The average annual percent change in waiver waitlist enrollment has increased by 9% over the previous 15 years.⁴¹ Without significantly more waiver spots or new approaches for allocating these important services equitably, disparities will likely become more pronounced. Although the waitlist is intended to be a cost-saving strategy, this strategy may increase long-term costs and contribute to poorer health outcomes overall. Additional strategies regarding how to best apply limited funding should be considered.

Further research is needed to better understand these findings and inform future interventions. For example, studies are needed to examine the factor of age such as examining the impact of having the NC I/DD Waiver in childhood and during the transition to adulthood versus having it in adulthood only. Evaluation of age, geographic, and racial and ethnic disparities among individuals on the waiting list is also needed, as is the examination of the barriers and facilitators to timely addition to the list for people of racial and ethnic minority groups and from rural settings. Further evaluation of cultural, practical, and condition-based needs and biases that may serve as barriers or facilitators to pursuit of the NC I/DD Waiver is necessary. Economic evaluations are also necessary to examine cost savings associated with the NC I/DD Waiver and the negative consequences of unequal distribution based on race/ethnicity. What is the cost to a Black individual with I/DD of delayed access to an NC I/DD Waiver slot that could provide them with \$50,000 of services per year? What is the cost to the state of having individuals with I/DD in an institution as opposed to with their family? Future studies of HCBS I/DD Waiver programs are needed to evaluate the policies currently in place and to inform future policies to promote equitable allocation of waiver slots and return on investment.

CONCLUSION

Innovative strategies are needed to provide equitable access to the North Carolina intellectual and developmental disabilities (I/DD) Waiver and provide the services needed to the 14,000 people with I/DD currently on the Registry of Unmet Needs in North Carolina. Further research is critical to examine the national landscape of Home and Community-Based Services (HCBS) I/DD waivers and inform policies to ensure equitable distribution of these waivers. Strategies are needed to assure that potential recipients have knowledge of HCBS waivers and have equitable and timely access to HCBS I/DD waiver services.

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