

NEW DISABLED SOUTH

# Uncovering Disparities in Georgia's HCBS Waiver Waitlist

What the NOW/COMP waiver waitlist can tell us about racial disparities in services for Georgians with Intellectual/Developmental Disabilities.

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## Introduction

Racial disparities are a pervasive issue within the realm of public healthcare. Research has found that we see similar trends when examining health and healthcare disparities among individuals with intellectual and developmental disabilities (IDD) when comparing them to non-disabled adults and children<sup>1</sup>. Research has uncovered notable racial disparities in mortality rates among those with an IDD. The findings reveal that Black individuals with IDD have a higher rate of death (1.56) compared to their White counterparts (1.06)<sup>2</sup>. When examining this through a racial and ethnic lens, it is found that those poor health outcomes expand beyond mortality rates, but are true for several aspects of health. Individuals with IDD belonging to racial and ethnic minority groups experience heightened exposure to adverse social determinants of health<sup>3</sup>. For us to adequately advocate for equitable policies and services, we must examine the intersection between race and IDD status, and how these factors impact an individual's ability to receive proper services and care.

Most available research on racial and ethnic disparities among children and adults with IDD is conducted at the national level. However, in-depth state-level analyses are severely lacking, particularly in the southern region of the United States. In this study, we chose to examine the ethnic and racial disparities for people with IDD attempting to utilize public healthcare in the state of Georgia.

In the state of Georgia, Home and Community Based Services (HCBS) waivers serve as a critical lifeline for people with IDD who need long-term care and support, intending to enhance their quality of life while allowing them to remain in their communities. However, troubling disparities have emerged in the distribution and utilization of these waivers, with stark disparities in access and availability based on race. This report delves into the racial disparities in Georgia's HCBS waiver system, shedding light on the distinct experiences and challenges faced by various racial groups, with a focus on Black/African Americans, in accessing essential care and services. By analyzing the data, identifying contributing factors,

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<sup>1</sup> Magaña, S., Parish, S., Morales, M. A., Li, H., & Fujiura, G. (2016). Racial and ethnic health disparities among people with intellectual and developmental disabilities. *Intellectual and developmental disabilities*, 54(3), 161–172. <https://doi.org/10.1352/1934-9556-54.3.161>.

<sup>2</sup> Boyle, C.A., Decouflé, P. and Holmgreen, P. (1994), Contribution of developmental disabilities to childhood mortality in the United States: a multiple-cause-of-death analysis. *Paediatric and Perinatal Epidemiology*, 8: 411–422. <https://doi.org/10.1111/j.1365-3016.1994.tb00480.x>

<sup>3</sup> Magaña, S., Heydarian, N., & Vanegas, S. (2022). Disparities in healthcare access and outcomes among racial and ethnic minoritized people with intellectual and developmental disabilities. *Oxford Research Encyclopedia of Global Public Health*. <https://doi.org/10.1093/acrefore/9780190632366.013.288>

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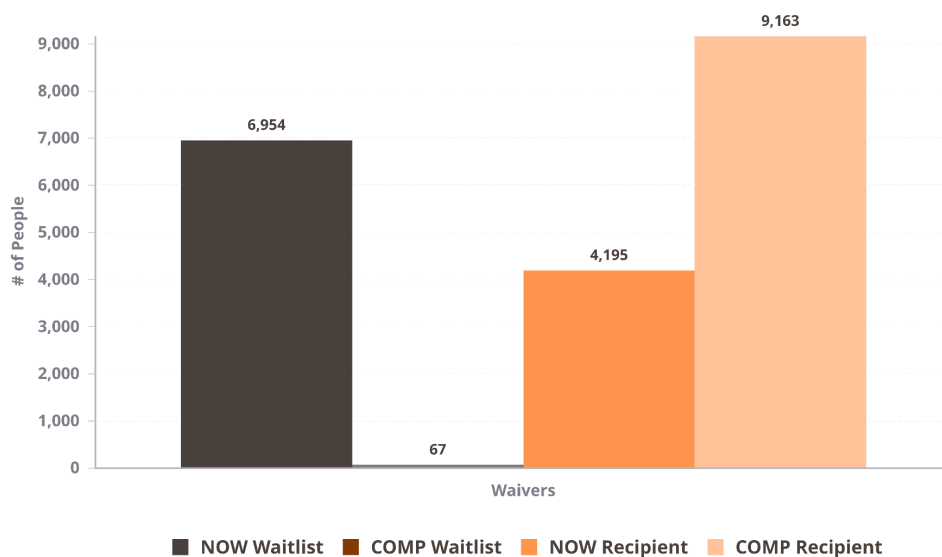
and proposing potential solutions, this report seeks to initiate informed discussions and advocate for a more equitable and inclusive approach to providing vital support to all Georgians, irrespective of their racial background.

## The Problem

Georgia's New Option Waiver Program (NOW) and Comprehensive Support Waiver Program (COMP) are Medicaid waivers that serve as instruments to facilitate the provision of essential services to individuals in the convenience of their own homes and communities. These waivers aim to promote an alternative to receiving care in nursing homes and institutional settings. Presently, there exists a waiting list of more than 7,000 individuals with IDD who anticipate the acquisition of the necessary resources enabling them to live comfortably, independently, and within their respective communities. Among Georgians with IDD who possess a Medicaid waiver, a significant 68.6% are beneficiaries of the COMP, while the remaining 31.4% are enrolled in the NOW program.

## Comparison of NOW/COMP Waiver Waitlist and Granted Waivers in Georgia

99% of Waitlisted Georgians Are for NOW Program Services



There is a notable discrepancy evident in the figures when scrutinizing the waitlist for NOW/COMP waivers. Specifically, a staggering 99% of individuals on the waitlist are awaiting a NOW waiver, while a mere 1% are anticipating a COMP waiver. While it is

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accurate that recipients of COMP waivers are acknowledged by the state to possess more severe disabilities and necessitate a higher level of care, such a significant disparity in numbers is quite revealing. This is particularly noteworthy as we delve into an examination of the racial composition of both the NOW/COMP waitlist and the list of recipients.

### **Racial Composition of NOW/COMP Waivers**

Note: The third largest group on the waitlist was categorized as "Unknown/Refused", representing approximately 25% of the remaining list. The remaining racial demographics did not have a significant enough representation to conduct a comprehensive analysis.

Research and empirical evidence consistently highlight significant racial disparities in access to appropriate and equitable healthcare services for individuals with IDD. Black individuals often encounter a range of challenges, including limited access to diagnostic tools, delayed identification of disabilities, and a lack of culturally sensitive care. These obstacles not only impede timely diagnosis and intervention but also hinder the provision of personalized support and resources crucial for effective management and improved quality of life. Furthermore, racial biases within the healthcare system can lead to unequal treatment, insufficient attention to unique needs, and a lack of awareness about the intersectionality of race and disability. These systematic disparities reflect broader societal inequalities and require a concerted effort to address and rectify the racial inequities within the field of IDD care.

During the more in-depth examination of the racial composition of the NOW/COMP waiver waitlist, specific statistical parameters were established for the purpose of our investigation. For the majority of our comparative analysis, we focused on racial categories that constitute a proportion exceeding 5% of Georgia's population and more than 10% of the state's waiver recipient or waitlist population. As a result of the existence of an additional category labeled as "Unknown/Refused" which meets the criteria, our attention has been directed solely towards Black/African American and White/Caucasian individuals with IDD residing in Georgia.

### Racial Disparity Between Those Receiving Waivers and Those On the Waitlist

Race	AIAN	Asian	Black	Multiracial	NHPI	Other Race	Unknown/ Refused	White	Total
On Waitlist	12	156	2700	102	6	221	1789	2035	7021
Receiving Waiver	4	118	5749	98	12	293	662	6422	13358
<b>Disparity %</b>	<b>300</b>	<b>132.20</b>	<b>46.96</b>	<b>104.08</b>	<b>50</b>	<b>75.43</b>	<b>270.24</b>	<b>31.69</b>	
Disparity Rate									<b>15.28%</b>

Note: The provided disparity rate pertains to individuals of Black and White ethnicity residing in Georgia.

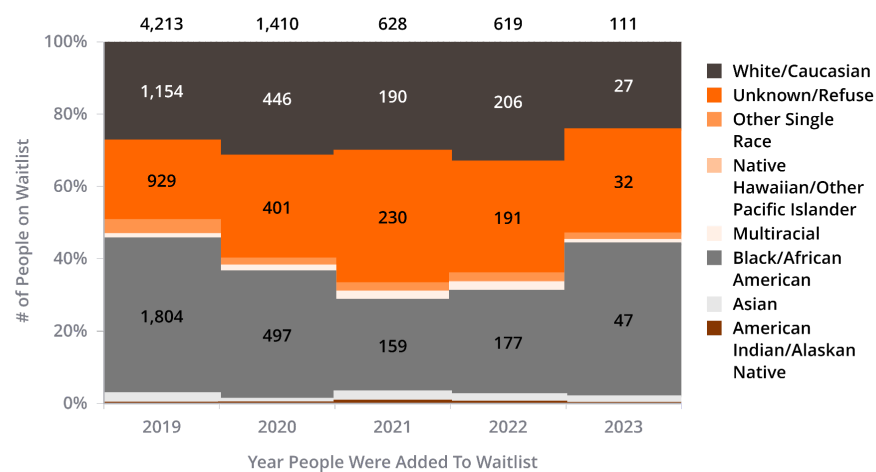
Source: New Disabled South Research Team analysis of State of Georgia NOW/COMP waiver waitlist 2019-2023

At the start of this project, we conducted a thorough analysis to determine if the perceived problem regarding racial disparities was indeed valid. It comes as no surprise that we did discover the presence of such disparities. Specifically, we identified a significant gap of 15.28% between individuals of Black and White races who qualified for an IDD waiver in Georgia. While this finding is concerning, it does not provide sufficient context regarding the extent to which this disparity manifests itself within the waitlist.

So, we dug more.

### HCBS Waiver Waitlist Duration in Georgia by Race

60% of Waitlist Entries Date Back to 2019 or Earlier



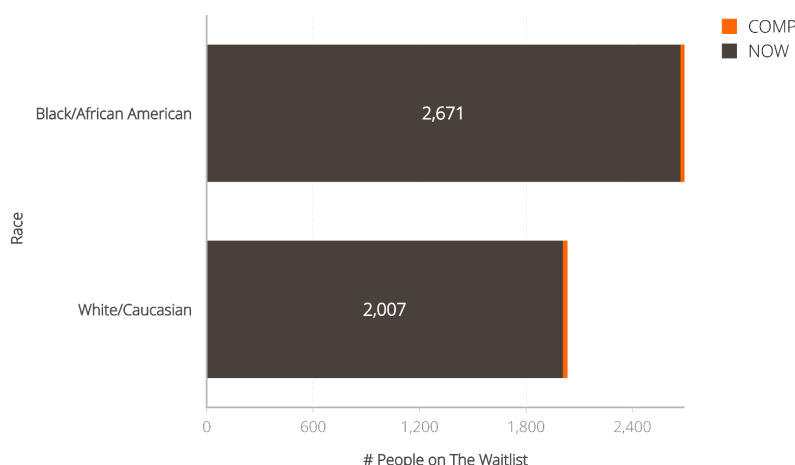
Note: Only values for Black, White and Unknown/Refused racial identities are shown.

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One of the significant concerns we have observed regarding the NOW/COMP waiver waitlist is the extended duration individuals spend on the waitlist. Currently, more than 60% of the individuals on these waitlists have been on them since 2019 or even earlier. The state of Georgia recognizes that these services are essential for individuals with IDD in the state, leading us to question the cause of this backlog. It is a factual reality that at least 4,213 individuals requiring home and community-based services have been denied access to this right for a period of at least four years.

## There are more Black Georgians on the NOW/COMP Waiver Waitlist

There are 27.9% more Black Georgia residents on the NOW/COMP waiver waitlist than White Georgians



Note: This is examining races that make up more than 5% of Georgia's population and more than 10% of the state's Waiver recipient or waitlist Source: New Disabled South Research Team analysis of State of Georgia NOW/COMP waiver waitlist 2019-2023

When examining the specific demographics of Georgia's waiver waitlist, a glaring disparity emerges, revealing that there are 27.9% more Black Georgians awaiting waivers compared to their white counterparts. This alarming discrepancy underscores a persistent pattern of racial inequity in access to critical healthcare resources. The disproportionate representation of Black individuals on the waiver waitlist is indicative of systemic barriers within the public healthcare system that hinder their ability to access and navigate necessary services. This disparity is not isolated but reflects a broader trend wherein Black communities face systemic challenges in obtaining adequate healthcare resources and services at a level commensurate with their white counterparts.



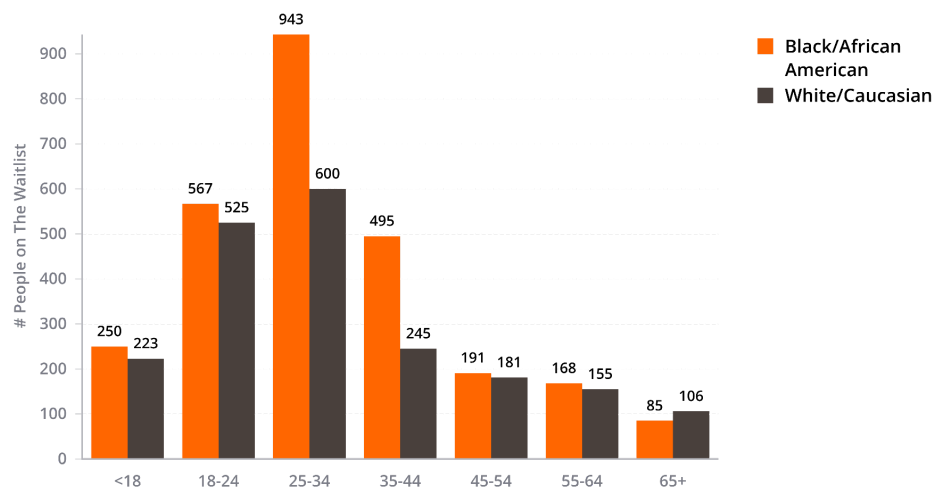
**Racial Demographics of NOW/COMP Waiver Waitlist and Recipient List:  
Black and White Populations**

	Black/African American	White/Caucasian
NOW Waitlist	<b>2677</b>	2007
NOW Recipient	<b>1937</b>	1783
COMP Waitlist	23	<b>28</b>
COMP Recipient	3812	<b>4639</b>

With a significant portion of the funding allocated towards the COMP waiver, it is evident that the majority of individuals on the waiver waitlist are seeking enrollment in the NOW Program. Additionally, it is noteworthy that a large proportion of those who have received waivers are participants in the COMP Program. Therefore, it is crucial to analyze these lists in order to gain insights. Upon examination, it becomes apparent that there is a higher representation of Black individuals both on the waitlist for a NOW waiver and as recipients of NOW waivers.

## HCBS Waivers Age Range Distribution for Black and White Georgians

Disparity Highlight: More Black Individuals on Waitlist Across Age Ranges, Except 65+



Note: Age ranges created by New Disabled South Research team.  
Source: State of Georgia NOW/COMP waiver waitlist 2019-2023

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As we analyze the age range distribution of Black and white Georgians, who represent approximately 68% of the individuals on the waitlist, a pattern emerges where Black individuals consistently have a higher number of people on the waitlist compared to their white counterparts. The most significant disparities are observed in the age groups of 25-34 and 34-44, with percentage differences of 44.5% and 67.6% respectively.

In contrast, when examining the list of waiver recipients, we find that white individuals account for a significantly higher percentage than Black recipients. For the age ranges of 25-34 and 34-44, there is a percentage difference of 13% and 4.5% respectively. Of particular note is the percentage difference for the age range of 18-24, where there is a 40.63% advantage for white recipients. Conversely, for the same age range, Black individuals are the majority on the waitlist with an 11.4% difference.

While it is important to acknowledge that the state of Georgia does not have the intention of purposely withholding services from Black residents with intellectual and developmental disabilities, it is crucial to recognize that disparities exist within the system. By acknowledging and addressing these disparities, we can work towards formulating more equitable policies and strategies.



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## The Solution

### Budget Surplus

Georgia is currently boasting an astounding \$10 billion budget surplus<sup>4</sup>. Addressing the current waiver waitlist, a fraction of this surplus, specifically less than 1%, would be required to fund one-third of the waitlist, demonstrating the feasibility of using a small portion of the surplus to address critical social needs. Moreover, this surplus offers a strategic opportunity to enhance vital public services and infrastructure, ensuring a higher standard of living for Georgia's residents. It is worth considering that, in theory, the state has the financial capacity to cover the entire waitlist for less than 2% of this surplus, underlining the potential for impactful investments in crucial areas such as healthcare, education, and social welfare. Responsible allocation of this surplus can drive substantial positive change and propel Georgia towards a brighter and more equitable future for all its citizens.

Notably, the state's expenditure for NOW/COMP waivers has consistently grown every year since 2019. In fact, the state recently witnessed a significant surge in spending on its Medicaid waiver program, directing a substantial \$15 million to support close to 1000 waivers<sup>5</sup>. Nonetheless, despite these efforts, there remains an insufficiency in meeting the demand, despite the state's capacity to invest further.

In addition to increasing funding for waivers, it is imperative that we address the issue of inadequate wages for our caregivers in the state. A significant challenge faced by individuals with IDD is the difficulty in finding a caregiver even after being approved for a waiver following years of waiting. This is mainly due to the fact that caregivers in the state are currently being paid well below a fair and livable wage.

At present, Georgia offers a pay rate of \$10 an hour for Direct Service Providers (DSP). However, data from the Bureau of Economic Analysis reveals that the cost of living in Georgia amounts to \$47,406 annually<sup>6</sup>, with housing costs ranging from \$1,084 to \$1,957 per month<sup>7</sup>. Unfortunately, at a \$10 per hour wage, our DSPs are earning a gross monthly income of only \$1,600, assuming they can work full-time hours. This is an unacceptable situation that must be addressed promptly.

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<sup>4</sup> Farr, K. GOVERNOR'S OFFICE OF PLANNING AND BUDGET. (2023). *THE GOVERNOR'S BUDGET REPORT Amended Fiscal Year 2023 and Fiscal Year 2024*. State of Georgia.

<sup>5</sup> Ibid.

<sup>6</sup> Bureau of Economic Analysis/US Department of Commerce. (2023). *Personal Consumption Expenditures by State, 2022*. BEA 22-50. US Department of Commerce

<sup>7</sup> SoFi. (2021, November 16). Cost of living in Georgia (2023). <https://www.sofi.com/cost-of-living-in-georgia/>

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Disability justice advocates and organizations have consistently advocated for a pay raise for DSPs to a minimum of \$18 per hour. This reasonable request, amounting to a projected expenditure of \$91 million, represents less than 1% of the current budget surplus in the state of Georgia. Although it is commendable that the state has decided to allocate more funds towards reducing the waitlist, it is imperative for the state to take a comprehensive approach to this matter. This approach should encompass recognizing the need for DSPs to receive a wage that enables them to maintain a decent standard of living and promotes fairness in compensation.

Georgia has the opportunity to effectively resolve this issue by allocating additional funding towards NOW/COMP waivers within the state. Georgia possesses the necessary financial resources to adequately meet the needs of individuals with intellectual and developmental disabilities.