



Georgia's NOW/COMP Waiver Waitlist: The Time is Now

Introduction

Georgia's NOW/COMP waivers provide essential services to individuals with intellectual and developmental disabilities (ID/DD). These waivers play a crucial role in supporting individuals who require home and community-based services to live with greater independence, dignity, and an enhanced quality of life within their communities. This legislative history sheds light on the distribution of NOW/COMP waivers over the past eleven years, highlighting changes in waiver distribution, as well as challenges and achievements.

Background

A NOW/COMP waiver is Medicaid-funded money for services tailored to individuals with developmental disabilities. While Medicaid typically covers essential healthcare costs like doctor visits, hospital expenses, medication, therapy, and certain medical supplies, the NOW/COMP Waiver enables the utilization of Medicaid funds to cover additional services like care provided either in the individual's home or within the community, with funding from both state and federal sources.

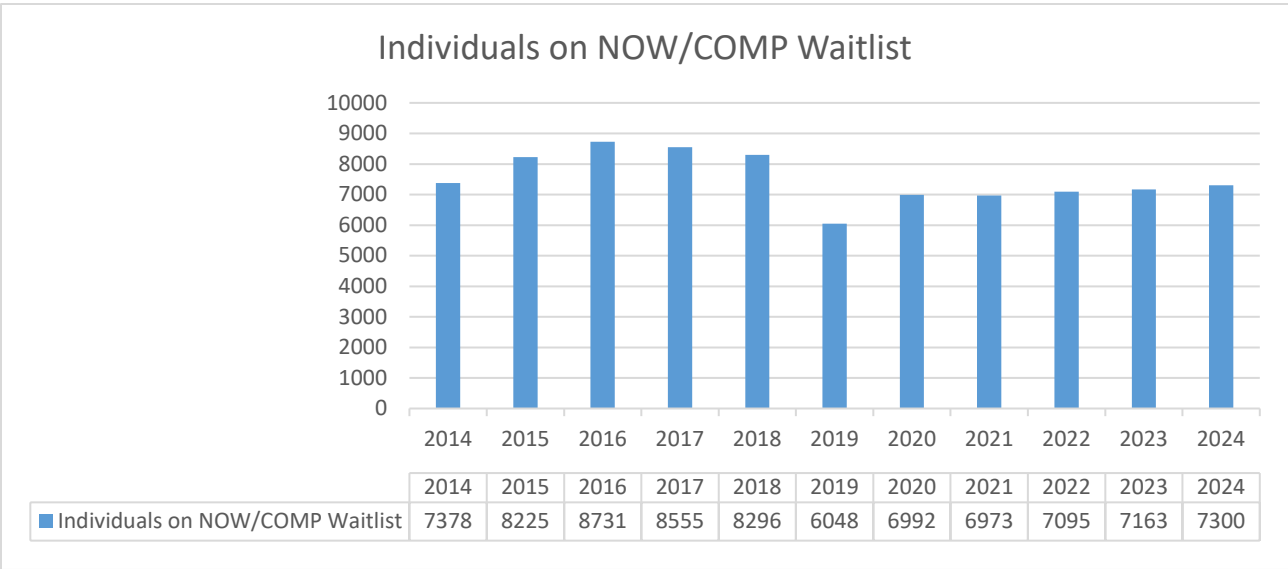
The New Options Waiver (NOW) is designed for individuals who do *not* require 24-hour care. It has a limit of \$25,000 annually per person and primarily benefits people with disabilities living with family members or in their own homes. On the other hand, the Comprehensive Supports Waiver (COMP) caters to individuals who need a wider range of out-of-home services or intensive in-home support. It is also employed for people transitioning from institutions into community living.

The target group for the NOW/COMP waiver program is individuals who have a developmental disability with significant impact, which could include conditions such as cerebral palsy, epilepsy, autism, or other neurological conditions. These individuals must meet specific eligibility criteria to access the home and community-based services provided by Georgia's NOW and COMP waiver programs. The eligibility criteria encompass categorical eligibility, a documented diagnosis of an intellectual disability or closely related condition, the need for care comparable to that provided in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-ID), and the appropriateness of home and community-based services as an alternative to institutional care.

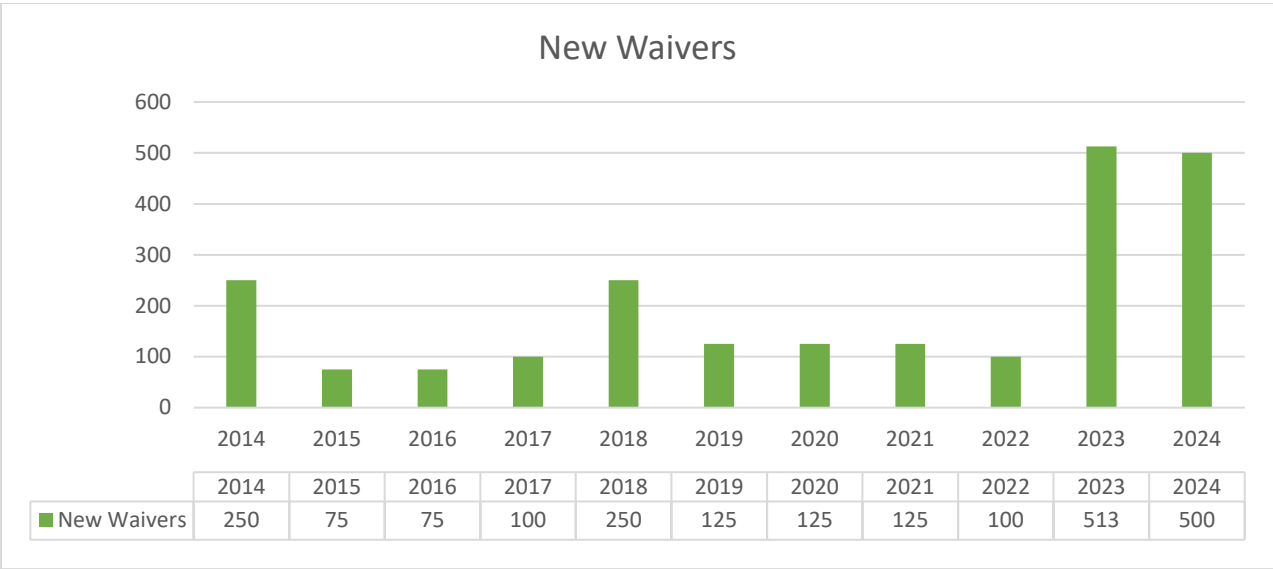
This legislative history of the NOW/COMP Waiver program is largely an exploration of the challenges it faces. A significant challenge is the waitlist (also referred to as the planning list) for these waivers, which encompasses the thousands of Georgians in need of support who are unable to receive services at the time that they apply. As of January 2024, over 7,300 individuals were on the waiting list, emphasizing the pressing need for legislative action and reform. This legislative history also delves into the broader context of the care economy in Georgia, including issues related to a shortage of direct-service professionals and low wages that impact service availability and quality.

NOW/COMP Over the Years – 2013 to 2024

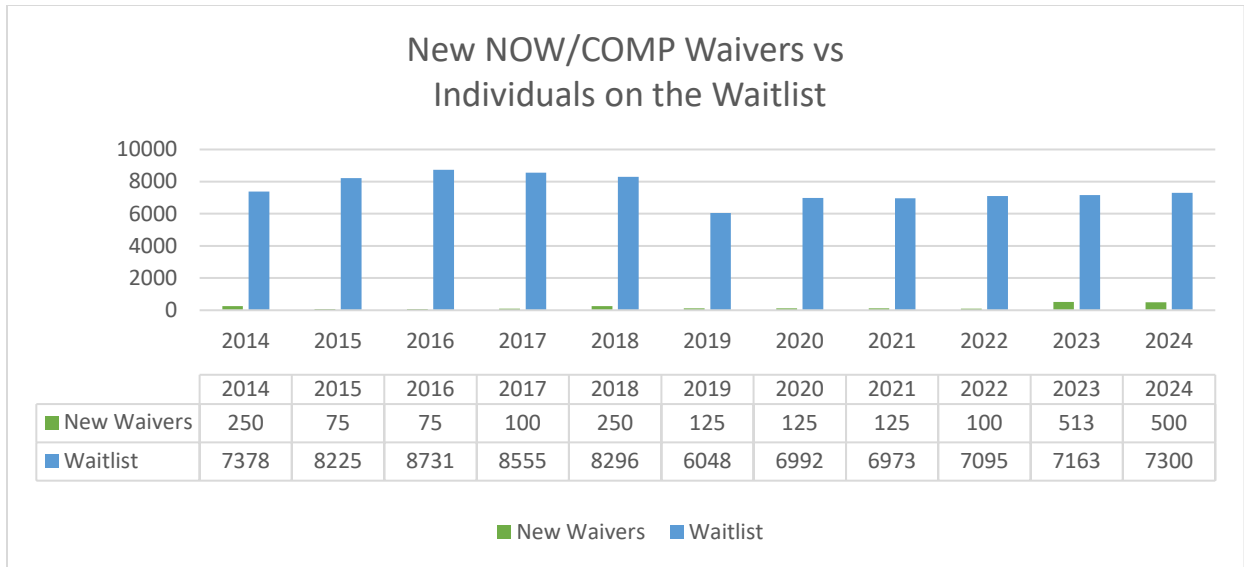
NOW and COMP waivers are distributed by the Department of Behavioral Health and Developmental Disabilities (DBHDD) who also keeps track of NOW/COMP waitlist. The NOW/COMP waitlist has ebbed and flowed over the past decade but has never dropped below 6,000 individuals. Likewise, the distribution of waivers over the past eleven years has not advanced linearly, with the number of new waivers budgeted annually changing in response to the political and economic climate.



Source: [Department of Behavioral Health and Developmental Disabilities](#)



Source: [Governor’s Office of Planning and Budget](#)

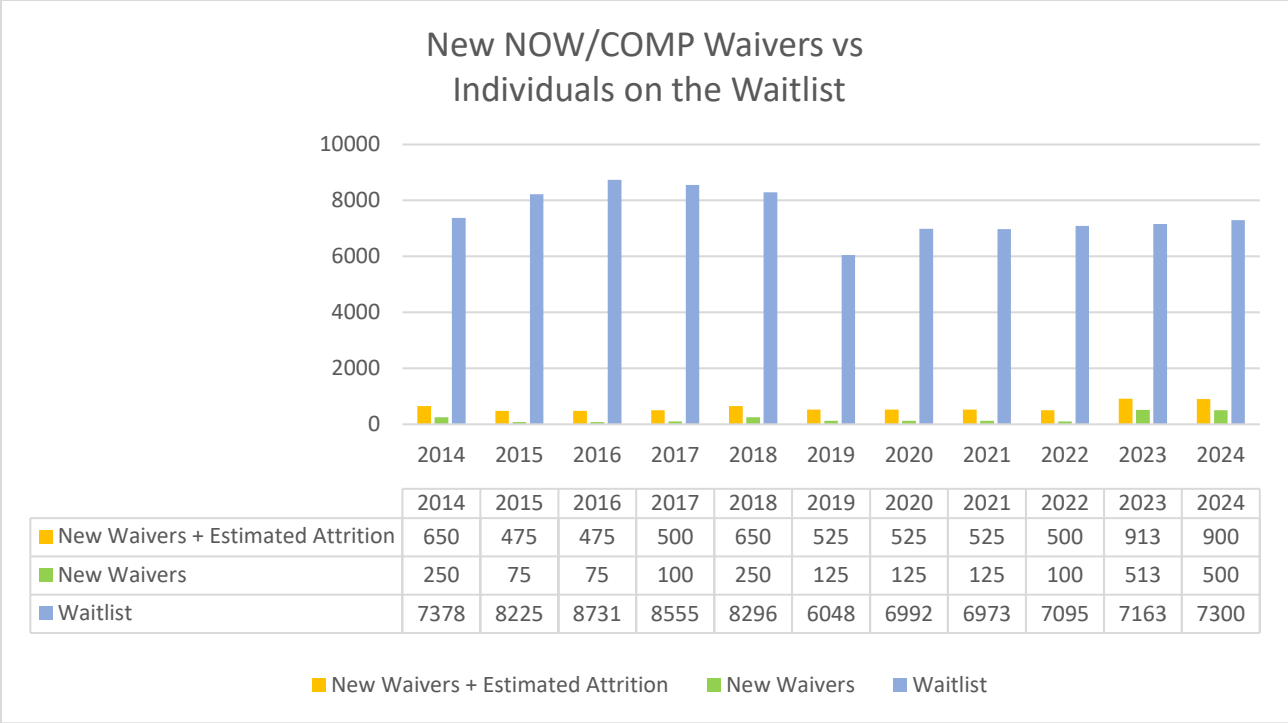


Source: [Department of Behavioral Health and Developmental Disabilities, Governor’s Office of Planning and Budget](#)

As demonstrated in the chart above, the number of NOW/COMP waivers in Georgia has consistently fallen short of meeting demand, resulting in a consistently high waitlist for essential services. Despite the pressing needs of individuals with disabilities and their families, the distribution of waivers has failed to keep pace. This shortage has left many vulnerable individuals in Georgia waiting for critical support, facing delays that can have a profound impact on their quality of life.

DBHDD estimates that roughly 400 individuals ‘roll off’ of NOW/COMP waivers annually.¹ This attrition is attributed either to mortality or moving out of the state, and the funds are reallocated as waivers to individuals on the waitlist. The impact of this estimated attrition on waitlist numbers is demonstrated in the chart below.

¹ Commissioner Kevin Tanner’s presentation to the Georgia General Assembly, 2024. [Georgia General Assembly](#).



DOJ, the Olmstead Decision, and Waivers

In the past eleven years, waiver distribution spiked in 2014, and later in 2023 and 2024. The 2014 increase in distribution in can be attributed to a 2010 Department of Justice (DOJ) settlement stemming from a lawsuit under the Americans with Disabilities Act and the Supreme Court’s Olmstead decision. This settlement aimed to address Georgia's provision of community services for individuals with mental illness and developmental disabilities.² The initial findings in 2009 revealed that Georgia was placing people with disabilities in state hospitals rather than offering community-based services, which violated ADA integration mandates and Olmstead, a 1999 landmark legal case that clarified and affirmed the rights of individuals with disabilities to live in the community rather than being unnecessarily institutionalized.³ Therefore, provisions were entered into the state budgets for an additional 1,150 waivers, which was reached in 2014 with the addition of 250 waivers. However, this spike in waiver funding did not make a sizeable impact on the waitlist, with the number of individuals remaining over 8,000 in 2015.

A 2010 settlement stemming from a lawsuit under the Americans with Disabilities Act and the Supreme Court’s Olmstead decision, an extension agreement has been established. This relates to Georgia's provision of community services for individuals with mental illness and developmental disabilities. The initial findings in 2009 revealed that Georgia was placing people with disabilities in state hospitals rather than offering community-based services, which violated ADA integration mandates. Recently, the department raised concerns about Georgia's compliance with the 2010 agreement, particularly regarding transitioning individuals from institutions to communities and overseeing community-based services' quality. Despite these concerns, given Georgia's substantial commitments outlined in the agreement, the department has opted to retract its motion to enforce the earlier agreement.

² Justice Department Reaches an Extension Decision, 2016. [US Department of Justice](#).
³ Analysis of Recent Downturns in the Georgia’s Medicaid Waiver Planning Lists, 2020. [GCDD](#).

In 2009, it was found that Georgia was putting people with disabilities in state hospitals instead of helping them in their own communities, which broke the rules of the Americans with Disabilities Act. Now, the government is worried that Georgia isn't doing enough to follow the 2010 agreement. They're especially concerned about how Georgia helps people move from hospitals to communities and how well they watch over community services. Even though there are worries, because Georgia has promised to do better, the government has decided not to push them too hard right now.

[The I/DD Study Committee and the 2,400 Waiver Ask](#)

In 2022, Senators Sally Harrell and John Albers led a Senate Study Committee on People with Intellectual and Developmental Disabilities and Waiver Plan Access. The result of this bipartisan committee was a series of unanimously approved recommendations for the 2023 legislative session based on information and testimony gathered through a series of public meetings around the state.

One of the key recommendations was to fund 2,400 waiver slots in the Fiscal Year (FY) 2024 budget—a number that reflected a third of the NOW/COMP waiting list at the time. The vision of the committee was to eliminate the waitlist entirely in three years. However, as listed above, only 513 and 500 waivers were allocated in the FY 2023 and 2024 budgets, respectively. While this is the largest spike in waiver funding in the past decade, it is also insufficient both to meet the needs of Georgians with I/DD and to fulfill the Study Committee's recommendations.

[The NOW/COMP Waiting List Today – Challenges & Solutions](#)

As of January 2024, the landscape of NOW/COMP waivers in Georgia paints a complex picture. With over 13,000 Georgians benefitting from these waivers, it might seem like a significant step towards enhancing the lives of individuals with I/DD. However, the reality is more nuanced. While funding from the waivers is a critical aspect, it's only one side of the equation. The availability of services is equally important, and this is where a significant challenge emerges—the direct support professional (DSP) crisis.

DSPs play an indispensable role in the lives of Georgians with disabilities, providing a broad spectrum of daily support services. These services range from habilitation and healthcare to personal care, transportation, employment assistance, and more, all aimed at facilitating individuals' active participation in their communities and enabling self-directed lives.

The demand for DSPs is steadily growing, driven by factors such as population growth, increased life expectancy among those with disabilities, the aging of family caregivers, and the transition from institutional to community-based services, as mandated by federal legislative measures. However, this growing demand significantly outpaces the available workforce. High vacancy rates and voluntary turnover, compounded by low wages, limited benefits, minimal training, and inadequate supervision all create a barrier to establishing a stable and sustainable workforce in this critical field.

In Georgia, the situation is dire, with an alarming annual turnover rate of 50%, and only 64% of staff staying in their positions for more than a year. The average hourly wage for DSPs stands at a mere \$10.30, well below the national average of \$11.76, and far from meeting the living wage standards in

Georgia. Additionally, a minimal percentage of DSPs receive paid time off, and less than half have access to health insurance.⁴

This DSP crisis not only poses a substantial challenge to the service system but also places individuals in need of assistance at considerable risk. It contributes to unreasonably long waiting lists for services and pushes some to consider more costly institutional models of care outside their homes.

As Georgia grapples with the impact of this DSP crisis, legislative actions and policy changes become increasingly imperative to ensure that the NOW/COMP waiver program fulfills its mission of providing comprehensive and accessible support to those in need. A 2022-2023 rate study highlighted the necessity for a 62% increase in wages as part of an overall 40% increase in provider reimbursements, suggesting that DSPs should be making \$16.70 per hour to address this pressing issue. However, this rate study line-item disregarded in the budget, preventing implementation of higher rates, and therefore sustaining the crisis. **The most important step that legislators can take this year to overcome the DSP crisis and ensure successful delivery of NOW/COMP waivers is to support the \$79 million in the Governor’s budget allocated for implementation of the rate study and for DBHDD to supplement this allocation with \$28 million of ARPA funds to reach the \$107 million needed to fully fund the rate study.**

In addition to the DSP workforce shortage, one argument underpinning consistently low requests is that the administrative capacity of DBHDD to distribute NOW/COMP waivers is limited. While this is true, and staffing levels have not yet reached their pre-COVID levels, strategic implementation of waivers is possible and can make more of a difference in the waitlist and the lives of Georgians. Especially with full implementation of the rate study, we recommend that the legislature provide funding for 2,400 new NOW/COMP waivers to jumpstart DBHDD’s waiver distribution and ensure that not only the individuals who need the waivers most, but also the individuals who will need waivers later, are able to receive services. The current system of waiting until individuals are in desperate need, rather than pre-empting the need with proactive and restrictive waiver distribution, ensures that waivers cost more than they need to. With 2,400 waivers, individuals could receive services straight out of high school—this would mean that their caregivers can continue to work, more DSPs would be employed, and the individual would be able to participate in their communities. **Fully integrating Georgians with I/DD into the community and making a real difference in the 7,000+ person waitlist can only happen if the legislature allocates funding for a significant number (recommended 2,400) of NOW/COMP waivers in the FY 2025 budget.**

Another challenge of the NOW/COMP waiting list was highlighted in a recent study⁵ by New Disabled South, which found that there are 27.9% more black Georgians awaiting waivers compared to their white counterparts. The overrepresentation of black individuals on the waiver waitlist highlights systemic obstacles within the public healthcare system that prevent access to essential services by minority populations. The primary solution here, other than examining internal processes and external factors for structural bias, is **to shorten and/or eliminate the waitlist by providing more NOW/COMP waivers.**

⁴ *State of the Workforce Survey Report, 2021.* [National Core Indicators.](#)

⁵ *Uncovering Disparities in Georgia’s HCBS Waiver Waitlist, 2023.* [New Disabled South.](#)