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Care in Crisis: The Home and Community-Based Services (HCBS) System in South Carolina

Introduction

Home and Community-Based Services (HCBS) waivers¹ are critical in enabling people of all ages with different types of disabilities to live independently in their communities rather than being forced into institutional settings like nursing homes, state hospitals, and group homes. These essential services are funded by the state government through Medicaid, yet long waitlists, severe workforce shortages, and chronic underfunding have created major barriers to access.

Medicaid is the largest funder of long-term services and supports (LTSS) in the United States, covering more than two-thirds of all HCBS services². South Carolina's Medicaid HCBS system remains among the most restrictive and underfunded in the country. The 2023 LTSS Scorecard from the American Association of Retired Persons (AARP), South Carolina ranked 49th nationwide, receiving particularly low scores in affordability, access, and community integration.³ In 2024, the state had the third-longest HCBS waitlist, with 33,892 people stuck on its waitlist, trailing Texas and Florida.⁴

¹ Centers for Medicare & Medicaid Services, *Home & community-based services*, Medicaid.gov, <https://www.medicaid.gov/medicaid/home-community-based-services/index.html>.

² Centers for Medicare & Medicaid Services, *Long-term services & supports (LTSS)*, Medicaid.gov], <https://www.medicaid.gov/medicaid/long-term-services-supports/index.html>.

³ AARP, *South Carolina: 2023 LTSS State Scorecard*, LTSS Choices, <https://ltsschoices.aarp.org/scorecard-report/2023/states/south-carolina#toc-explore-data>.

⁴ KFF, *Medicaid HCBS waiver waiting list enrollment by target population and whether states screen for eligibility*, <https://www.kff.org/medicaid/state-indicator/medicaid-hcbs-waiver-waiting-list-enrollment-by-target-population-and-whether-states-screen-for-eligibility/>.

In South Carolina, Home and Community-Based Services (HCBS) waivers are managed by two state agencies: the South Carolina Department of Health and Human Services (SCDHHS) and the South Carolina Department of Disabilities and Special Needs (SCDDSN)⁵. SCDHHS serves as the administrative authority for the Community Choices Waiver, which had 22,734 enrolled participants in 2023, the HIV/AIDS Waiver with 468 enrollees, the Mechanical Ventilator Waiver with 46 enrollees, and the Palmetto Coordinated System of Care for Children, which had 77 enrollees. According to Russell Morrison, Director of the Office of Waiver and Facility Services, SCDHHS waivers do not have formal waiting lists because they operate without enrollment caps. However, they do maintain a “pending list” or “interest list” for those awaiting approval. As the Kaiser Family Foundation notes, assessing the existence of a waiting list is difficult, because states frequently change terminology, utilizing referral list, interest list and registry as other means of describing lists of people who are interested in, but not receiving, services. SCDDSN oversees the Intellectual Disability/Related Disabilities (ID/RD) Waiver, Community Supports Waiver, and Head and Spinal Cord Injury Waiver, all of which have a waitlist⁶. The ID/RD Waiver has the longest waitlist, with 29,862 people waiting for HCBS waivers in 2023. By 2024, this number had surged to 33,559, reflecting a worsening crisis in service availability.⁷

⁵ Conner, A. M., Haire, E., Howell, K., & Sanderson, B. *Opportunities for South Carolina to Strengthen Home and Community-Based Services for People with Disabilities*. Disability Rights South Carolina & South Carolina Institute of Medicine and Public Health, 2023.

⁶ South Carolina Department of Disabilities and Special Needs, *Medicaid home and community-based waiver services*, <https://ddsn.sc.gov/services/medicaid-home-and-community-based-waiver-services>

⁷ KFF, *Medicaid HCBS waiver waiting list enrollment by target population and whether states screen for eligibility*, <https://www.kff.org/medicaid/state-indicator/medicaid-hcbs-waiver-waiting-list-enrollment-by-target-population-and-whether-states-screen-for-eligibility/>.

This report analyzes South Carolina's HCBS system, examining the impact of long waitlists, workforce shortages, and disparities in access across the state. Conducted by New Disabled South in collaboration with the National Domestic Workers Alliance (NDWA), this research combines quantitative data with the lived experiences of disabled people and care workers. By integrating statistical analysis with firsthand accounts, the report highlights systemic barriers. It underscores the urgent need for policy reform and increased funding to ensure equitable access to home and community-based services.

Regional and Racial Disparities in HCBS Access

The urgent need for change in South Carolina's HCBS system is evident, as research from neighboring states highlights deep racial disparities. A New Disabled South report on Georgia's HCBS waitlist found that Black people were disproportionately placed on waitlists, making up 27.9% more of the waitlist population than their white counterparts⁸. While similar data for South Carolina is not publicly available, the 2024 KFF report underscores the broader regional crisis, with over 540,000 people across the South waiting for HCBS services. This staggering number suggests that systemic barriers are preventing marginalized communities from accessing essential care. Older adults of color, in particular, are disproportionately represented in the near Medicaid-eligible population, increasing their risk of delayed or inadequate services.⁹ Without immediate policy interventions, these disparities will continue to widen, leaving the most vulnerable populations without the support they need to live independently and with dignity.

⁸ New Disabled South, *Waitlist Disparities Report*, <https://www.newdisabledsouth.org/reports/waitlist-disparities>

⁹ NORC & The SCAN Foundation, *Understanding Historically Marginalized & Minoritized Populations in the Forgotten Middle*, NORC at the University of Chicago, 2024.

Direct Care Worker Shortage

A strong and stable care workforce is essential to making a meaningful impact in reducing South Carolina's HCBS waiver waitlist. Personal care attendants and home health aides play a crucial role in supporting older adults and disabled people with daily activities such as eating, dressing, bathing, and household tasks. Their work allows many people to remain in their homes and communities rather than being forced into institutional care. However, without enough direct support professionals (DSPs), personal care attendants, and home health aides, thousands of people remain stuck on the waitlist, unable to access the services they need. Russell Morrison, Director of the Office of the Waiver and Facility Services at SCDHHS, participated in this research as a stakeholder interviewee and identified the direct care workforce shortage as one of the most significant barriers to reducing waitlist times and addressing disparities in service access. Addressing this workforce crisis is critical to ensuring that South Carolina's HCBS system can meet the growing demand for services and provide essential care to those who need it most.

The severity of this crisis is reflected in a 2024 KFF report, which found workforce shortages in all 50 states, but South Carolina's workforce shortage is particularly extreme. The demand for home care workers is expected to rise sharply, with 66,500 new job openings projected by 2032¹⁰. However, low wages continue to drive high turnover rates. In early 2022, South Carolina Medicaid reimbursed provider agencies only \$14 per hour for personal care services, but has since increased their reimbursement rates by 80% to \$25 per hour.¹¹ However, it is unclear whether these increased payments have led to higher wages. Provider agencies are only required to pay the federal minimum wage of \$7.25/hr and the median salary for home health aides in South Carolina remains just \$13.62 per hour¹², making it difficult to attract and retain workers. According to the South Carolina Department on Aging, the number of adults aged 60 and above is projected to increase to 1,450,487 by 2030. Compounding the issue, the number of seniors aged 65 and above with at least one disability exceeded 295,000 in 2020 and is expected to increase¹³. Without immediate investment in better wages, benefits, and recruitment efforts, South Carolina's HCBS system will remain severely understaffed, leaving disabled people and their families without the care they urgently need.

¹⁰ KFF, *Payment Rates for Medicaid Home and Community-Based Services: States' Responses to Workforce Challenges*, <https://www.kff.org/medicaid/issue-brief/payment-rates-for-medicaid-home-and-community-based-services-states-responses-to-workforce-challenges/>.

¹¹ CMS, 1915(c) Waiver Applications, 2022-23.

¹² PHI, *Workforce Data Center: South Carolina Employment Projections*], <https://www.phinational.org/policy-research/workforce-data-center/#states=45&var=Employment+Projections>.

¹³ South Carolina Department on Aging, *State Plan on Aging 2021-2025*, 2021

The best way to recruit and retain home care workers is to pay a living wage. Twenty-seven states have adopted wage pass-through laws to address workforce shortages, ensuring that Medicaid reimbursement increases go directly to worker wages¹⁴. The South Carolina Institute of Medicine & Public Health (IMPH)¹⁵, issued a report in 2022, *The Direct Care Workforce in Long-Term Care Settings: Recommendations for Recruitment and Retention*. Their first recommendation is to ensure that Medicaid reimbursement results in increased compensation, and the authors urged South Carolina to adopt a “wage pass-through” measure, which requires providers to pass on Medicaid dollars in the form of increased wages to the workforce. Additionally, the Centers for Medicare & Medicaid Services (CMS) recently finalized the “Ensuring Access to Medicaid” rule, which will require States to ensure that provider agencies allocate at least 80% of Medicaid payments for home care services¹⁶ towards compensation for direct care workers.¹⁷ Instituting a rule that 80% of payment rates to providers go towards compensation would ensure direct care workers earn \$20 per hour in wages and benefit (likely an \$18/hr base wage), a far more competitive wage than is currently the norm. Despite these proven policy solutions, South Carolina has yet to implement a similar measure, making it even harder for people to receive care.

¹⁴ Institute for Health and Justice Equity, *Wage Pass-Through Report*, accessed [date], <https://ihje.org/our-work/reports/wage-pass-through/>.

¹⁵ The South Carolina Institute of Medicine & Public Health (IMPH) is an independent entity serving as an informed nonpartisan convener around the important health issues in our state, providing evidence based information to inform health policy decisions.

¹⁶ Home Health Services, Personal Care Services and Homemaker Services

¹⁷ Centers for Medicare & Medicaid Services. (2024). *Biden-Harris administration takes historic action to increase access to quality care and support families*. CMS. <https://www.cms.gov/newsroom/press-releases/biden-harris-administration-takes-historic-action-increase-access-quality-care-and-support-families>

Transparency and Data Challenges in South Carolina's HCBS System

To better understand the structure and demographics of South Carolina's HCBS waitlist, New Disabled South submitted a Freedom of Information Act (FOIA) request to the South Carolina Department of Disabilities and Special Needs (SCDDSN). While SCDDSN provided some general data, they refused to release racial and ethnic breakdowns, despite internally collecting this information. This lack of transparency makes it nearly impossible to assess racial disparities in HCBS access, hindering efforts to address inequities in the system.

Additionally, a FOIA request was submitted to the South Carolina Department of Health and Human Services (SCDHHS) to clarify details about people on the “pending list,” including how long it takes for applicants to move from initial application to eligibility determination and ultimately receive services. In response, the agency stated that such an analysis would require excessive speculation, explaining that not all Medicaid applicants complete the process, not all who complete the process are financially eligible, and not all Medicaid-eligible applicants meet the level-of-care criteria for HCBS waiver services. This vague response highlights a critical lack of data transparency, making it difficult to assess processing times, service accessibility, and systemic barriers within South Carolina's HCBS system.

The FOIA data received on August 23, 2024 from SCDDSN, indicated that 20,296 people were on the HCBS waiver waitlist. In contrast, a 2024 KFF report recorded a higher figure, 33,992¹⁸ people waiting for services, including 33,559 specifically awaiting the IDD waiver. In 2023, KFF data showed 41,078 people on the waitlist, but this figure included people on the “interest list” for waivers managed by the South Carolina Department of Health and Human Services (SCDHHS). The 2024 KFF data excludes the “interest list”, which accounts for part of the discrepancy. These inconsistencies underscore the urgent need for standardized, publicly accessible data to accurately assess the scope of South Carolina’s HCBS crisis and drive evidence-based policy reforms.

Limitations of Measuring Unmet Needs with HCBS Waitlist Data

While HCBS waitlists provide a general indication of people who may need services they are not receiving, they are an incomplete measure of unmet need¹⁹. Waitlists do not account for people who require services in states where those services are not covered and, therefore, have no formal waitlist. Moreover, some states do not screen for HCBS eligibility before placing them on waitlists, making it difficult to determine true unmet demand. The size and scope of a waitlist reflect a state’s policy decisions, including which populations it chooses to serve, the specific services it offers, the level of funding it allocates, and the availability of workers to deliver care²⁰.

¹⁸ Kaiser Family Foundation. (n.d.). *Medicaid HCBS waiver waiting list enrollment by target population and whether states screen for eligibility*. Kaiser Family Foundation.

¹⁹ Musumeci, M., & Chidambaram, P. (2024, February 15). *A look at waiting lists for Medicaid home and community-based services from 2016 to 2023*. KFF.
<https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2023>

²⁰ KFF, *Payment Rates for Medicaid Home and Community-Based Services: States' Responses to Workforce Challenges*,
<https://www.kff.org/medicaid/issue-brief/payment-rates-for-medicaid-home-and-community-based-services-states-responses-to-workforce-challenges/>.

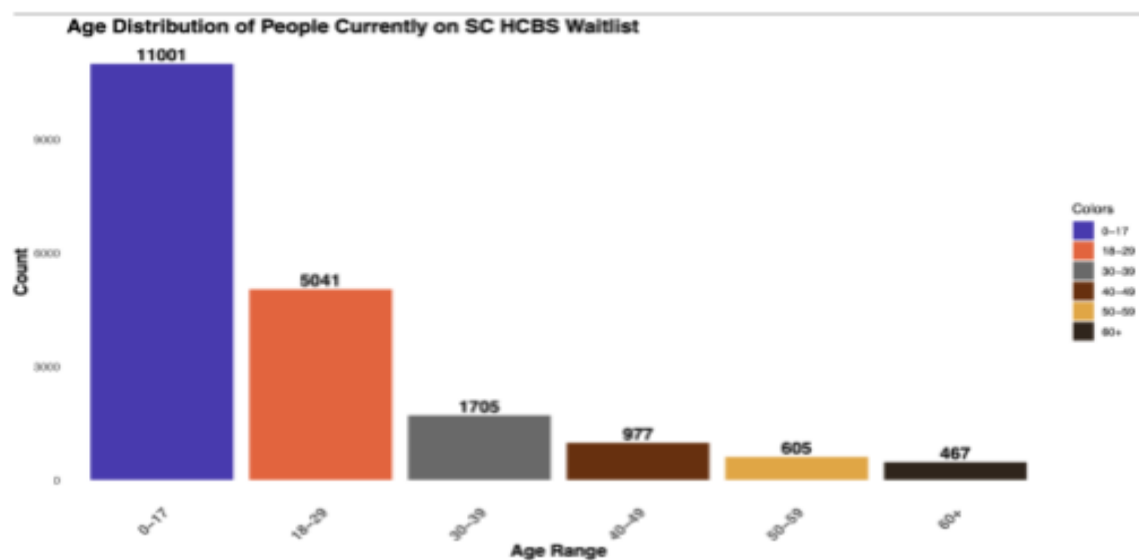
Another factor affecting HCBS availability is states' progress in meeting federal requirements for home and community-based care. The HCBS Settings Rule, established by CMS in 2014, requires states to ensure that Medicaid-funded home and community-based services truly support community living and integration, rather than isolating people in institutional settings²¹. However, states have faced delays in fully implementing these requirements. These delays impact how states allocate funding, prioritize services, and determine who qualifies for HCBS, all of which affect waitlist sizes and the accuracy of unmet need estimates.

Furthermore, some states do not maintain formal waitlists at all, instead using informal "registries" or "interest lists," making it even harder to quantify unmet needs²². The lack of standardized reporting across states, combined with ongoing delays in HCBS expansion, complicates efforts to assess the true demand for services. Despite these limitations, no alternative measures currently exist to accurately assess the full extent of unmet needs in home and community-based services. However, as CMS continues efforts to monitor and enforce HCBS compliance, improvements in waitlist data collection and standardization could eventually provide a clearer picture of service gaps.

²¹ Administration for Community Living. (n.d.). *Home and Community-Based Services (HCBS) settings rule*. U.S. Department of Health and Human Services. <https://acl.gov/programs/hcbs-settings-rule>

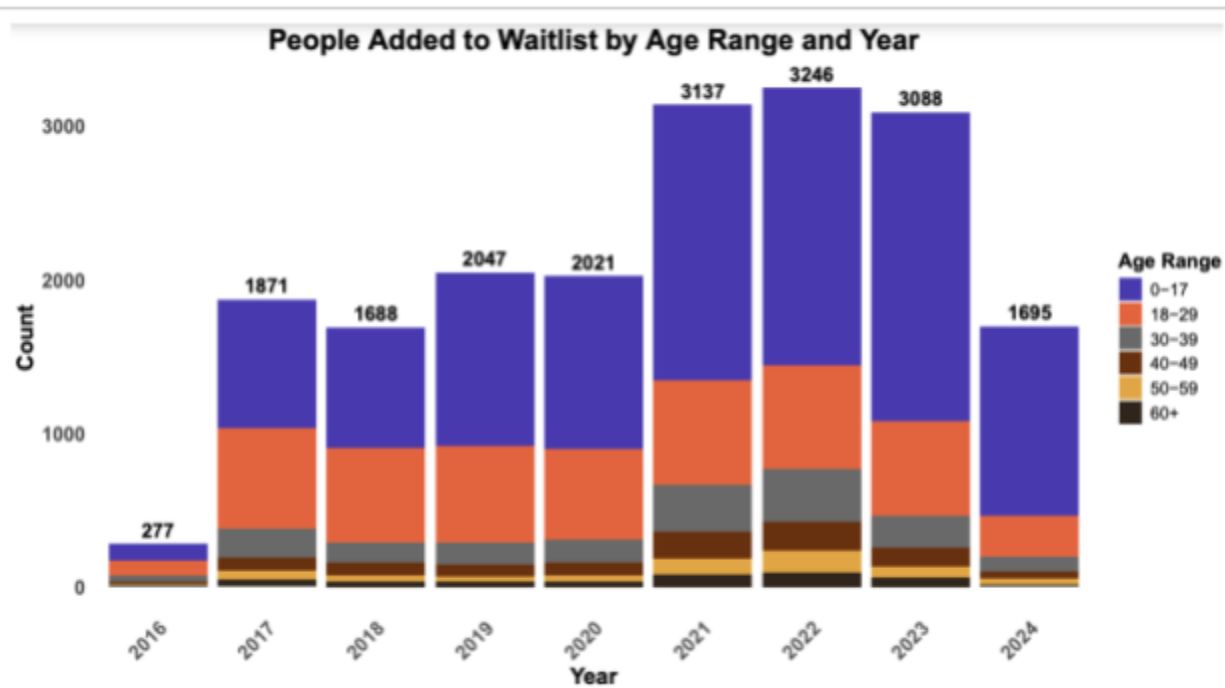
²² Musumeci, M., Chidambaram, P., & Ochieng, N. (2024, January 22). *A look at waiting lists for Medicaid Home and Community-Based Services from 2016 to 2024*. KFF. <https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2024/>

Age and Geographic Trends in the HCBS Waitlist



The bar graph, titled “Age Distribution of People Currently on the SC HCBS Waitlist,” visualizes the number of people in six age categories: 0-17, 18-29, 30-39, 40-49, 50-59, and 60+. The x-axis displays these age ranges, while the y-axis represents the count of people on the waitlist. Each age group is represented by a distinct colored bar, with bar heights corresponding to the number of people in each category. The data shows 11,001 people in the 0-17 age range, 5,041 in the 18-29 group, 1,705 in the 30-39 range, 977 in the 40-49 range, 605 in the 50-59 group, and 467 in the 60+ category.

The aggregated data revealed critical trends in South Carolina’s HCBS waitlist. According to DDSN data, most people waiting for services are young, with children aged 0–17 making up the largest group at over 11,000, young adults aged 18–29 form the second-largest group, with just over 5,000 people. As age increases, the number of people on the waitlist declines, with the smallest group being those aged 60 and older. This distribution highlights the overwhelming demand for services among children and young adults, emphasizing the urgent need for early intervention, expanded support options, and more substantial community-based services.



The bar graph, titled “People Added to the HCBS Waitlist by Age Range and Year,” illustrates the number of people added to the HCBS waitlist annually from 2016 to 2024. The data is categorized into six age groups: 0-17, 18-29, 30-39, 40-49, 50-59, and 60+. The x-axis displays the years, while the y-axis represents the count of people added to the waitlist. Each year is represented by a stacked bar, with distinct colors indicating the contributions of each age group. The total height of each bar reflects the overall number of people added to the waitlist that year. The yearly totals are as follows: 277 people were added in 2016, 1,871 in 2017, 1,699 in 2018, 2,047 in 2019, 2,021 in 2020, 3,137 in 2021, 3,246 in 2022, 3,088 in 2023, and 1,695 in 2024.

An analysis of waitlist additions by age group and year reveals fluctuating trends, with notable spikes in the years following the 2020 COVID-19 pandemic, when more than 3,000 people were added. Interestingly, the most significant increase occurred in the 60+ age group, suggesting evolving needs among older adults. Meanwhile, the number of younger people added to the waitlist, mainly those aged 0–17 and 18–29, remained steady, reflecting the persistent demand for HCBS services among children and young adults.

Geographic Distribution and Regional Needs



This color-coded map of South Carolina illustrates the distribution of people on the Home and Community-Based Services (HCBS) waitlist across the state's counties. Each county is shaded to reflect the density of people waiting for services, with distinct colors indicating low, medium, or high numbers. Lexington County, prominently shaded in orange, has the highest number of people on the waitlist.

Using this data, we created a color-coded map that visualizes the number of people on South Carolina's DDSN HCBS waitlist by county. This map categorizes counties into low, medium, and high waitlist levels, revealing localized service access challenges. Lexington County has the highest number of people on the waitlist, signaling a critical area of need. Census data shows that Lexington County²³ has a rapidly growing population and a high percentage of families with children, which likely drives the demand for services.

²³ USA Facts. (n.d.). *Lexington County population and demographics*. USA Facts. <https://usafacts.org/data/topics/people-society/population-and-demographics/our-changing-population/state/south-carolina/county/lexington-county/>

This geographic analysis is essential for ensuring equitable resource distribution and addressing regional disparities in HCBS access. Integrating demographic data with waitlist trends provides a clearer understanding of the systemic barriers affecting people awaiting services. These insights can inform targeted strategies to improve HCBS delivery across South Carolina and ensure resources are directed where needed most.

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Listening to People on the HCBS Waitlist: What We Learned

To deepen our understanding of how Home and Community-Based Services (HCBS) waitlists affect disabled people in South Carolina, we expanded our quantitative analysis with qualitative research. This mixed-methods approach combined demographic data with in-depth interviews to examine how systemic and social factors shape the experiences of both disabled people and their caregivers. By integrating these perspectives, this research highlights the structural inequities, such as economic and racial disparities, that impact access to HCBS services in South Carolina.

We conducted in-depth interviews with 11 people currently on the HCBS waitlist. Most (80%) identified as African American, while 30% identified as white. Geographically, 60% lived in rural areas, 20% in urban communities, and 30% in suburban locations. Gender representation was relatively balanced, with 50% identifying as female and 60% as male. Participants ranged in age from 26 to 65, with the majority (60%) between 26 and 35 years old, followed by 40% aged 36 to 45, and 10% aged 56 to 65.

These interviews provided critical insights into people's challenges within the HCBS system, revealing personal struggles and systemic barriers. Each interview was carefully analyzed and coded for themes, allowing for a deeper examination of the patterns and inequities within South Carolina's HCBS system.

Key Themes from HCBS Waitlist Participant Interviews

Mental Health Impacts of Delayed Services

Several critical themes emerged from interviews with HCBS waitlist participants, with mental health impacts and systemic barriers appearing in every interview. Every participant reported struggles with their mental health, compounded by the challenges of navigating a broken system—long wait times, lack of communication, and uncertainty about when or if they would receive services.

One participant described the experience as *"traumatizing—like a dark cloud hanging over me. It's affecting not just my mental and emotional health but also my physical well-being."* Another shared, *"My daily life is limited because of my disability, and without HCBS services, I can't do the things I enjoy, like my hobbies. I've become more introverted, staying home, feeling angry and bitter. I used to love going outside, traveling, and socializing, but now I'm stuck indoors."*

These reflections highlight the profound personal toll of South Carolina's HCBS waitlist crisis. They reveal how delays in care strip people of independence, connection, and overall well-being. The overwhelming distress expressed by participants underscores the urgent need for reforms that not only address logistical failures but also recognize the emotional and psychological harm caused by prolonged inaccessibility. Timely access to services is not just about meeting basic needs—it is essential to restoring dignity, autonomy, and quality of life for those waiting.

The Strain on Informal Caregiving

The reliance on informal caregiving emerged as a major theme in 90% of the interviews, with participants describing the immense strain placed on their family members and friends. With formal HCBS services delayed or unavailable, many families were forced to step in—often at great personal and financial cost.

One participant shared, *"It's a challenge every day. I've lost hope that things will change. My sister tries her best to help, but it affects her life too. She has to take time off work to look after me, and I feel like a burden. It also impacts our relationship because I lash out sometimes, which I don't want to do, but it's hard when I feel this way."* Another participant explained, *"My family feels burdened trying to care for me. They won't say it, but I know resentment can build up. It's just a lot, especially with my head injury."*

These accounts illustrate the profound emotional and logistical challenges faced by both disabled people on the waitlist and their caregivers. The strain of unpaid caregiving can lead to financial hardship, relationship tension, and mental health struggles for all involved. This underscores the urgent need to expand access to formal HCBS services, ensuring that disabled people receive the care they need without placing unsustainable burdens on their loved ones.

Financial Strain and the Need for Systemic Solutions

Financial strain was a significant issue, reported in 50% of interviews, as participants described the burden of paying for care out-of-pocket or relying on unpaid caregivers due to service delays. Many struggled to afford essential support, further compounding the stress of being on the waitlist.

Despite these challenges, 70% of participants offered meaningful recommendations, emphasizing the need for interim services and improved communication about waitlist status. Their insights highlight the urgent need for systemic change that not only addresses long-standing HCBS barriers but also provides immediate relief for those waiting. Strengthening financial support, expanding interim care options, and ensuring clearer communication are critical steps toward reducing the hardships faced by disabled people and their caregivers.

Challenges Faced by HCBS Care Workers

Financial and Workplace Barriers

Interviews with care workers employed by home health agencies, conducted in collaboration with the National Domestic Workers Alliance, revealed significant challenges within the Home and Community-Based Services (HCBS) system. These conversations provided firsthand insights into the difficulties faced by those delivering care, exposing systemic barriers that affect both the quality of services and the stability of the workforce.

Harriet Tucker, a 65 year old Black direct care worker who was born and raised in Columbia, South Carolina, has been working for home care agencies since 2017. Her wages started at around \$11 and have only increased to \$14/hr, she also explained she would have to work for 4 clients in order to work 50 hours a week. She explains, *“if you don't work you don't get paid. There are no paid holidays, no mileage or gas reimbursements for running errands. You need another income to survive being a caregiver. My health started declining on the job and I couldn't stand it as much as I used to, which was hard on me because I love my clients and they need me as much as I need them. I had surgery on my arms in 2020, the day before Thanksgiving and was out for 4 months. I couldn't earn any money from caregiving - we have no paid sick time or paid medical leave. I was only able to survive because of my Social Security payments. We need benefits like paid sick time and medical leave and higher wages”*.

A major concern among care workers was low wages, with starting pay typically ranging from \$7 to \$11 per hour and little opportunity for wage increases. Many workers struggled to afford basic necessities, leading some to take on additional jobs or accumulate debt, especially due to unreimbursed travel expenses. A 44-year-old Black woman from Richland County, who has been working as a home care provider since 2014, has dedicated nearly a decade to direct care. She explains how the burden of travel time became an overwhelming cost, stating, *“If the client was too far I wouldn’t take them on because the cost of travel to client and home would leave me and my family in debt. The client is always worth it but the pay was not. I couldn’t keep a full tank of gas because the travel was a lot financially.”* She explains, there were no gift cards or mileage stipends to offset expense of travel and the agency she worked for didn’t have any clients close to her residence.

Beyond financial hardships, care workers also faced a lack of essential benefits such as paid sick leave and holiday pay. These conditions contributed to high turnover rates and widespread burnout in the profession. Despite these challenges, many care workers remained dedicated to their roles, often driven by personal caregiving experiences or a deep commitment to providing compassionate care. Several workers reported serving clients with complex needs, including mobility impairments, dementia, and dependence on medical equipment, further underscoring the critical nature of their work. Sherry Durham, a 42 year old Black woman, born and raised in Columbia South Carolina, has been a home health aide for 1 years. She explains the financial hardships, *“I have to work 2 jobs and when I don't work, I don't get paid. It has been a struggle for me to provide for my family. I am doing something that I love to do when it comes to helping others and making sure they are able to stay at home and not go into a facility. I would like to let my South Carolina representatives know that I love the work that I do, but as a caregiver I can't survive off one part-time job with no paid time off and no benefits. I would also like them to know that the cost of living goes up every year and my pay doesn't. I want to continue working with the family that I'm working with and in order to do so I need a raise and a paid time off. The hours are also too low and I would like this job to be one full time job.”*

Policy Recommendations from Care Workers

Care workers identified key legislative priorities to improve their working conditions, including higher wages, mileage reimbursement, and access to comprehensive benefits. These recommendations align with the concerns of HCBS recipients, emphasizing the deep connection between the challenges faced by both care providers and those relying on services. Without better pay, benefits, and support, workforce shortages will continue to limit access to care.

These findings highlight the urgent need for systemic reforms to ensure that HCBS remains both accessible and sustainable. Investing in care workers is essential not only for improving job conditions but also for strengthening the overall HCBS system, ensuring that disabled people receive the reliable, high-quality support they need.

Survey Findings: Connecting Lived Experiences with Systemic Barriers in HCBS

Access

From November to December 2024, New Disabled South conducted an online survey to gather additional insights into the HCBS waiver waitlist in South Carolina. This survey expanded our understanding by capturing the perspectives of a broader group of people on the waitlist and their caregivers. The responses provided valuable context to complement our interviews and data analysis, offering a more comprehensive view of the challenges faced by those awaiting services.

Long Wait Times Reflect Systematic Underfunding

More than half of survey respondents reported waiting over five years for HCBS services, highlighting the severe underfunding of South Carolina's system. These long delays reflect national trends of underinvestment but are especially extreme in South Carolina, which has one of the longest HCBS waitlists in the country. As a result, many disabled people and their families face prolonged hardships, with worsening physical health, emotional distress, and financial strain due to the lack of timely support.

Equity Concerns in the Waitlist Process

Survey responses revealed significant disparities in South Carolina's HCBS waitlist system, with 30% of participants reporting unfair treatment due to race, geographic location, or socioeconomic status. These findings reinforce broader systemic inequities, highlighting the urgent need for reforms that ensure equitable access to services. Respondents from rural areas, for example, frequently cited the lack of service providers and the burden of long travel distances as additional barriers, further widening the gap in access.

In written responses, participants expressed deep frustration with the lack of transparency and communication in the waitlist process. Many reported receiving little to no updates on their status, making it difficult to navigate the system or plan for their needs. Key recommendations included creating user-friendly platforms to track waitlist progress, improving direct communication with those waiting for services, and establishing interim support programs for those facing extended delays.

This survey provided crucial insights that complement findings from interviews and quantitative data analysis, reinforcing the systemic barriers outlined in this report. Most respondents identified as disabled or chronically ill, further validating the lived realities of those directly impacted by HCBS policies. Reported wait times varied widely, with many waiting more than five years, underscoring that South Carolina has one of the longest HCBS waitlists in the nation due to chronic underfunding.

Participants overwhelmingly called for urgent reforms, including greater transparency, fairer treatment, and shorter wait times. These recommendations align with themes identified throughout the study, strengthening the case for policy changes that address equity, access, and the broader structural failures of South Carolina’s HCBS system. By integrating survey findings with in-depth interviews and aggregate data, this report presents a clear and compelling need for immediate action to reduce disparities and improve service delivery.

Policy Recommendations

- **Increase HCBS Funding and Transparency**

The state should require clear, publicly available demographic data on HCBS waitlists, including race and ethnicity, to ensure transparency and accountability in service distribution. Additionally, South Carolina must expand waiver slots beyond the 1,000 proposed in the governor’s 2024 budget²⁴, which falls far short of addressing the needs of the 33,892 people still waiting for services. Without significant increases in available slots, the backlog will persist, leaving thousands without essential care.

²⁴ State of South Carolina, Office of the Governor. (2025). *FY26 Executive Budget Book*. Columbia, SC: State of South Carolina

- **Strengthening Budgeting Authority for Self-Directed Care**

South Carolina should ensure that people receiving HCBS through self-directed care models have full budgeting authority over their allocated Medicaid funds.

This would empower disabled people and their caregivers to make decisions that best meet their needs, rather than being limited by restrictive agency-managed service models.

- **Adopt Wage Pass Through Policies**

To strengthen the HCBS workforce and improve care quality, South Carolina should require that at least 80% of Medicaid reimbursements for home care services go directly to worker compensation, aligning with CMS's new national standard. This would establish a minimum wage of at least \$18 per hour for direct care workers in Medicaid-funded HCBS programs to address low pay, reduce turnover, and ensure a stable, well-supported workforce capable of meeting the growing demand for services.

- **Offer workplace benefits and programs to improve direct care workforce recruitment and retention efforts**

To address rural workforce shortages and strengthen the HCBS system, South Carolina should reimburse travel costs for direct care workers to reduce financial barriers for those serving remote areas. Additionally, the state should provide education and training incentives to attract new workers into the field. Increased funding is also critical to improve worker benefits, such as paid sick leave and overtime pay, ensuring a more sustainable and supported workforce capable of meeting the needs of disabled people across the state.

- **Address racial and economic disparities**

South Carolina should conduct statewide racial equity audits to assess disparities in HCBS access and waitlists, ensuring that resources are distributed fairly. Additionally, targeted outreach efforts must be implemented to reach Black and Latinx communities, who are disproportionately affected by service gaps. These measures will help address systemic inequities and ensure that HCBS services are accessible to those who need them most.

- **Improve eligibility processing and waitlist management**

South Carolina must reduce bureaucratic barriers by streamlining the eligibility screening process to prevent indefinite delays that leave applicants stuck in a “pending list” status. Additionally, implementing a real-time tracking system would allow HCBS applicants to monitor their waitlist status online, improving transparency and helping people better navigate the system while they wait for essential services.

A System in Crisis: The Urgent Need for Change in South Carolina’s HCBS System

South Carolina’s HCBS system is failing to meet the needs of disabled people and families due to persistent underfunding, severe workforce shortages, and widespread inequities in access. Without immediate intervention, the state’s HCBS waitlist will continue to grow, deepening disparities and leaving thousands without critical services.

To create a sustainable and equitable HCBS system, South Carolina must take decisive action. Key reforms include expanding funding to reduce wait times, increasing transparency in the waitlist process, implementing wage pass-through policies to stabilize the workforce, and addressing systemic inequities that disproportionately impact marginalized communities. These changes are essential to ensuring that disabled residents receive the care and support they need to live with dignity and independence.

South Carolina’s already struggling HCBS system is facing an even bigger problem—significant cuts in federal funding. H.R. 1, An Act to Provide for Reconciliation Pursuant to Title II of H. Con. Res. 14 (also known as the One Big Beautiful Bill Act) (2025), which was signed into law by President Trump the House on July 4, 2025 and is would reduce federal Medicaid spending over a decade by an estimated \$911 billion ²⁵. When faced with Medicaid cuts, the Congressional Budget Office assumes states will cut payment rates to health care providers, limit optional benefits, and reduce enrollment. Home-based care for seniors and people with disabilities – including children – is among the first benefits states will cut. These cuts would be devastating, not just for South Carolina, but for the whole country. Most of South Carolina’s Medicaid funding (almost 70%) comes from the federal government. If that money is reduced, the state may have to raise taxes or cut other important services.

Right now, over 33,000 people in South Carolina are already waiting for care. Without federal support, even more people will be stuck waiting. Across the U.S., these cuts could mean that up to 7.8 million people lose access to home care services, 2.5 million care workers lose jobs or face pay cuts, and 17 million disabled and older adults are put at risk. Families who already provide unpaid care would be pushed past their limits. South Carolina ranks 49th in the nation for long-term care. Losing funding would make things worse—especially for people of color and low-income families—and undo years of progress in disability rights and fair access to care. These cuts must be stopped to protect the health, independence, and dignity of millions of people.

²⁵ [Allocating CBO’s Estimates of Federal Medicaid Spending Reductions Across the States: Enacted Reconciliation Package | KFF](https://www.kff.org/medicaid/allocating-cbos-estimates-of-federal-medicare-spending-reductions-across-the-states-enacted-reconciliation-package/)

<https://www.kff.org/medicaid/allocating-cbos-estimates-of-federal-medicare-spending-reductions-across-the-states-enacted-reconciliation-package/> Congressional Budget Office. (2021, February 10). *Policy approaches to reduce what commercial insurers pay for hospital and physician services*. <https://www.cbo.gov/publication/61461>

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- **Hearts for Home Care South Carolina**
- **American Association of Retired Persons (AARP)**
- **South Carolina Department of Health and Human Services**
- **University of South Carolina's Center for Disability Resources**
- **South Carolina Appleseed**
- **South Carolina Institute of Medicine and Public Health**

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