

DATA COMPANION

Long-Term Services and Supports: Policy Solutions for a Changing Landscape

2024 North Carolina Institute of Medicine Annual Meeting

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Long-Term Services & Supports

Long-term services and supports (LTSS) are care and services provided in the home, in community-based settings, or in facilities such as nursing homes for older adults and people with disabilities who need support due to: ¹

- Age (>50% of those 65+ will at some point need help with at least two activities of daily living)
- Physical, cognitive, developmental, or chronic health conditions
- Other functional limitations ²

National Estimates ⁴

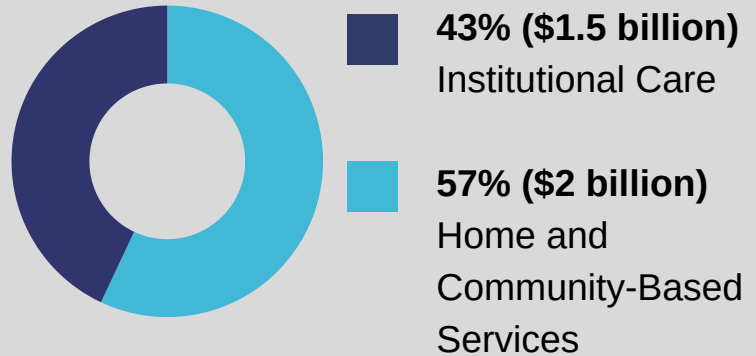
Nationally, more than **6 million** use LTSS delivered in home and community-based settings.

More than **2 million** use LTSS delivered in institutional settings.

An **unknown number** of people use unpaid LTSS provided by family, friends, or neighbors.

In 2022, Medicaid paid **61%** of total U.S. spending on all LTSS, followed by out-of-pocket spending (**17%**) and other public and private payers (**21%**).

In 2019, NC Medicaid expenditures for LTSS were **\$3.5 billion.** ³



Equity and Access Considerations ⁵

- Expected rates of LTSS need and use are highest among people with lifetime earnings in the **bottom income quintile**.
- Among people ages 65 and older, those who are **Black** or **Hispanic** are much more likely to develop moderate or severe LTSS needs than those who are White.

1) Centers for Medicare and Medicaid Services. "LTSS Models."

2) U.S. Department of Health and Human Services. "Economic Hardship and Medicaid Enrollment in Later Life: Assessing the Impact of Disability, Health, and Marital Status Shocks."

3) Centers for Medicare and Medicaid Services. "Medicaid LTSS Expenditures Report: FY 2019."

4) Kaiser Family Foundation. "10 Things About Long-Term Services and Supports (LTSS)."

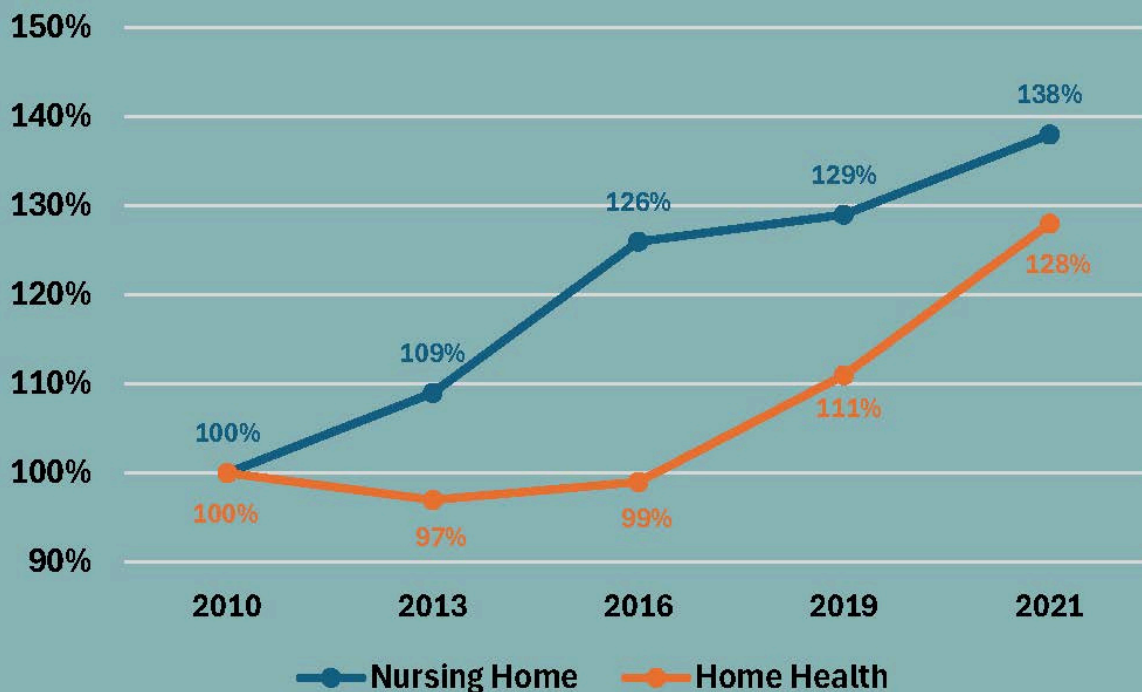
5) Center for Retirement Research at Boston College. "What Level of Long-Term Services and Supports Do Retirees Need?"

Costs of LTSS

Median Monthly LTSS Costs, 2023¹

Type of Service	NC	US
Homemaker Services	\$5,339	\$5,720
Home Health Services	\$5,339	\$6,292
Adult Day Services	\$1,484	\$2,058
Assisted Living	\$5,769	\$5,350
Nursing Home, Semi-Private Room	\$8,365	\$8,669
Nursing Home, Private Room	\$9,125	\$9,733

LTSS Costs in NC as a Percent of 2010 Costs¹



1) Estimates taken from Genworth Cost of Care Surveys.

Home and Community-Based Services

Home and community-based services (HCBS) include a variety of health and human services delivered in the home or community to address social isolation and other social determinants of health and help people stay in their homes for as long as possible.¹

Examples include:

- Home health services
- Community meals & home-delivered meals
- Personal care
- Home repairs & modifications
- Transportation

Rural populations tend to be older, poorer, and have more difficulty accessing HCBS compared to urban populations.^{2,3}

Rural-urban disparities in HCBS access may be due to:⁴

- limited **transportation** infrastructure
- **distances** separating providers and patients
- **provider shortages** in rural areas

HCBS By the Numbers (2023)

17,008 people with intellectual or developmental disabilities &

1,095 older adults and adults with physical disabilities

were on waiting lists for Medicaid HCBS waivers in North Carolina.⁵

More than
3 in 4

older adults want to stay in their homes and communities as they age.⁶

1) NC Department of Health and Human Services. "Home and Community-Based Services."

2) Agency for Healthcare Research and Quality. "National Healthcare Quality and Disparities Report chartbook on rural health care."

3) McAuley WJ, Spector W, Van Nostrand J. "Formal home care utilization patterns by rural-urban community residence"

4) Douthit N, Kiv S, Dwolatzky T, Biswas S. "Exposing some important barriers to health care access in the rural USA."

5) Kaiser Family Foundation. "Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility."

6) AARP. "Where We Live, Where We Age: Trends in Home and Community Preferences."

Older Adults in North Carolina

1 in 5 NC residents will be older than 65 by 2025.¹

In 2022 in North Carolina:

10%

of people aged
65+ lived below
100% of the FPL

7.7%

of people aged
60+ were food-
insecure

27%

of people
aged 65+
lived alone

17%

of people aged
65+ actively
participate in the
labor force

97%

of people aged
65+ lived in the
community

22%

of people aged
65+ are non-
White²

56%

of people
aged 65+ are
women*²

Geographic Considerations²

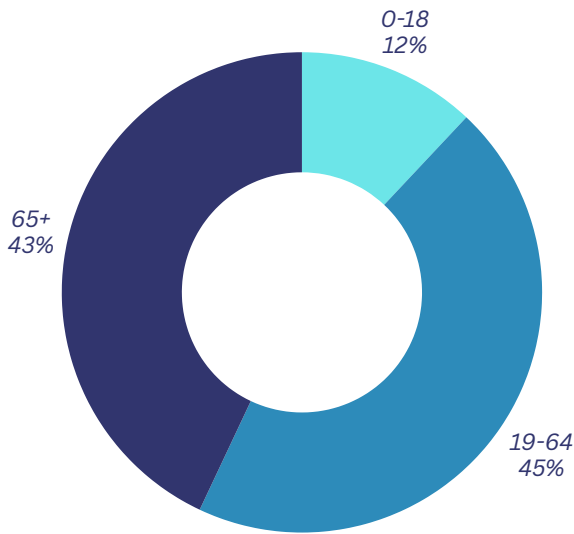
- **70 rural counties contain 38% of the 65-and-over population.**
- In contrast to urban counties, older adults living in **rural counties** are more likely to:
 - be African American;
 - have higher poverty and disability rates;
 - face challenges with transportation, housing, food insecurity, access to health care, and availability of broadband services.

1) NC Department of Health and Human Services. "Insights into Aging in NC."

2) NC Medical Journal. "Running the Numbers: How North Carolina's Population is Changing and Why It Matters."

*This gender difference widens with increasing age, as women have a higher life expectancy.

LTSS and Disability



Nationally, **over half** of LTSS Medicaid enrollees are younger than 65.¹

People who are younger than 65 but have **physical, cognitive, developmental, or other chronic health conditions or functional limitations** can use LTSS.²

The Right to Community Living³

In *Olmstead v. LC*, the 1999 Supreme Court held that people with disabilities have a **right to receive state-funded supports and services in the community** rather than institutions when:

1. the person's treatment professionals determine that community supports are appropriate;
2. the person does not object to living in the community; and
3. the provision of services in the community would be a reasonable accommodation when balanced with other similarly situated individuals with disabilities.

NC Medicaid LTSS Programs Supporting Community Living⁴

- Home Health & Personal Care Services
- Home Infusion Therapy
- Community Alternatives Program for Children (CAP/C)
- Community Alternative Program for Disabled Adults (CAP/DA)
- NC Traumatic Brain Injury Waiver
- NC Innovations Waiver

Barriers to Accessing LTSS for People with Disabilities⁵

- Insufficient Medicaid funding
- Waiting lists for services
- Uncoordinated system of services and supports
- Direct care workforce crisis

1) Kaiser Family Foundation. "10 Things About Long-Term Services and Supports (LTSS)."

2) North Carolina Council on Developmental Disabilities. "Medicaid Long-Term Services and Supports."

3) US Department of Health and Human Services. "Community Living and Olmstead."

4) NC Medicaid. "Fact Sheet: LTSS Service Descriptions and Eligibility Requirements."

5) American Association on Intellectual and Developmental Disabilities. "Long Term Supports and Services."

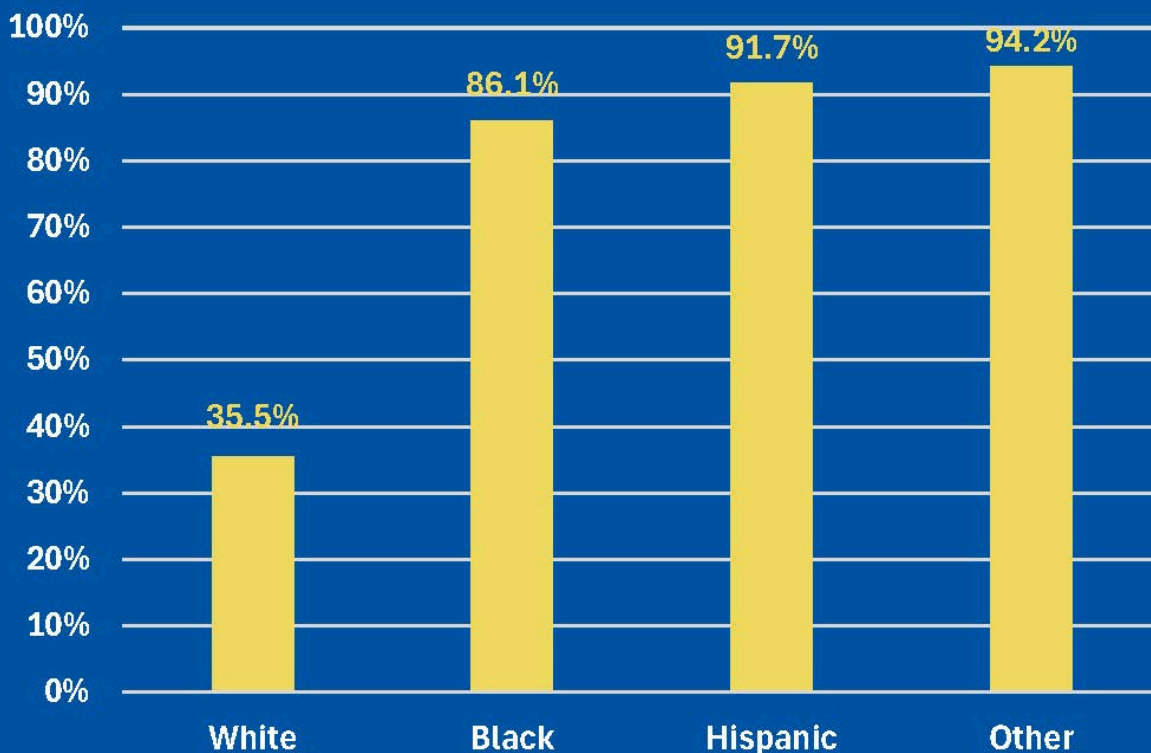
Support Needs by Race/Ethnicity

1 in 3 Black and Hispanic older adults reported difficulties with daily tasks compared to **1 in 5 White older adults**¹

Black and Hispanic older adults are **1.5 times** more likely to be without care support for one or more tasks than **White older adults**¹

Medicare beneficiaries of color are **more likely** to rely on unpaid informal caregivers for their home health care needs relative to **White beneficiaries**²

Percentage of Older Adults and Adults with Disabilities Eligible for Medicaid Home and Community-Based Services Who Report Unmet Needs²



Unmet needs include: assistance with daily activities, assistive technology, home modifications, transportation, and sufficiency of services for meeting user needs and goals.

1) Li J, Ha J, Hoffman G. "Unaddressed functional difficulty and care support among White, Black, and Hispanic older adults in the last decade."

2) Saulsberry L. "Medicare Beneficiaries of Color More Likely to Rely on Unpaid Informal Caregivers for Home Health"

2) Chong N, Akobirshoev I, Caldwell J, Kaye HS, Mitra M. "The relationship between unmet need for home and community-based services and health and community living outcomes."

Equity in LTSS

“**Equity** in a high-performing LTSS system means that high performance is shared across all groups, defined by race/ethnicity, gender identity, sexual orientation, age, disability status, and income, among others.”¹

Home and Community-Based Services

- Black & Hispanic older adults have unequal access to quality home and community-based services.³
- Obesity & heart disease, which are more prevalent among Black & Hispanic adults, may require more care than is available or covered.⁴
- Observer bias may impact who is assessed for & subsequently receives the LTSS for which they are eligible.⁵

Assisted Living

- Most assisted living facilities do not provide services that are eligible for Medicaid. Assisted living facilities are often built in higher-income and predominantly White communities, limiting access for older adults of color and those who are low-income.²

Nursing Homes

- Between 2011-2017, there was a **4.4% and 6.4% decline** in the number of nursing homes that serve any Black and Latino older adults, respectively, compared with a **2.26% decline** in those that serve only White older adults.⁶
- Black and Hispanic nursing home residents are more likely to reside in nursing homes that provide a lower quality of care.⁷

1) AARP. “Advancing Racial and Ethnic Equity in Long-Term Services and Support.”
2) Shippee TP, Duan Y, Baker MO, Angert J. “Racial/Ethnic Disparities in Self-Rated Health and Sense of Control For Older Adults Receiving Publicly Funded Home and Community-Based Services.”
3) Graham G. “Disparities in Cardiovascular Disease Risk in the United States.”
4) Shippee TP, Fabius CD, Fashaw-Walters S, et al. Evidence for Action: Addressing Systemic Racism Across Long-Term Services and Supports.”
5) Howard D, Sloane PD, Zimmerman S, Eckert JK, Walsh JF, Buie VC, Taylor PJ, Koch GG. “Distribution of African Americans in Residential Care/Assisted Living in Nursing Homes: More Evidence of Racial Disparity?”
6) Travers JL, Dick AW, Wu B, Grabowski DC, Robison J, Agarwal M, Perera GU, Stone PW. “A Profile of Black and Latino Older Adults Receiving Care in Nursing Homes: 2011-2017.”
7) Mack DS, Hunnicutt JN, Jesdale BM, Lapane KL. “Non-Hispanic Black-White Disparities in Pain and Pain Management among Newly Admitted Nursing Home Residents with Cancer.”

Direct Care Workforce in North Carolina

North Carolina will be required to fill

186,000+

direct care worker openings from 2018 to 2028.¹

\$13.62

The median hourly wage for direct care workers in North Carolina, 2022.¹

Women make up

92%

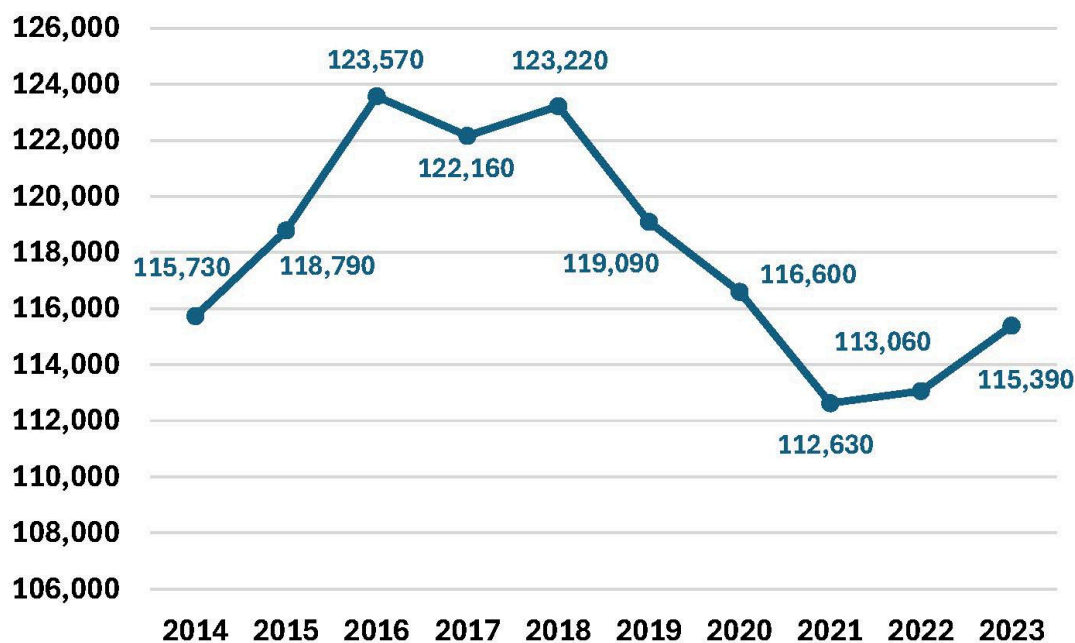
of the direct care workforce in North Carolina.¹

People of color make up

61%

of the direct care workforce in North Carolina.¹

Direct Care Worker* Employment in North Carolina, 2014-2023²



*Direct care workers include home health/personal care aides and nursing assistants

1) NC Department of Health and Human Services & NC Chamber of Commerce. "Investing in North Carolina's Caregiving Workforce: Recommendations to strengthen North Carolina's nursing, direct care, and behavioral health workforce, January 2024."

2) PHI. "Workforce Data Center." Last modified September 2024.

Issues Facing the Direct Care Workforce

In 2021, among home care workers in the United States:¹

42%

of health care workers lived in low-income households

55%

received public assistance

37%

were housing cost-burdened

15%

did not have health insurance

Challenges in North Carolina²

- Low wages
- Lack of benefits
- Inadequate training
- Lack of professional advancement
- Lack of respect and value
- Aging population

Residential care aides are disproportionately **women, people of color, and immigrants**, and therefore face greater risks of **discrimination** throughout their lives in areas including housing, education, employment, health care, and more.¹

Nursing assistants are nearly **8 times** more likely to experience **workplace injuries** than the typical U.S. worker.¹

More than **1 in 4 residential care aides** only worked **part time** in 2021, an increase from **1 in 5** in 2020.¹

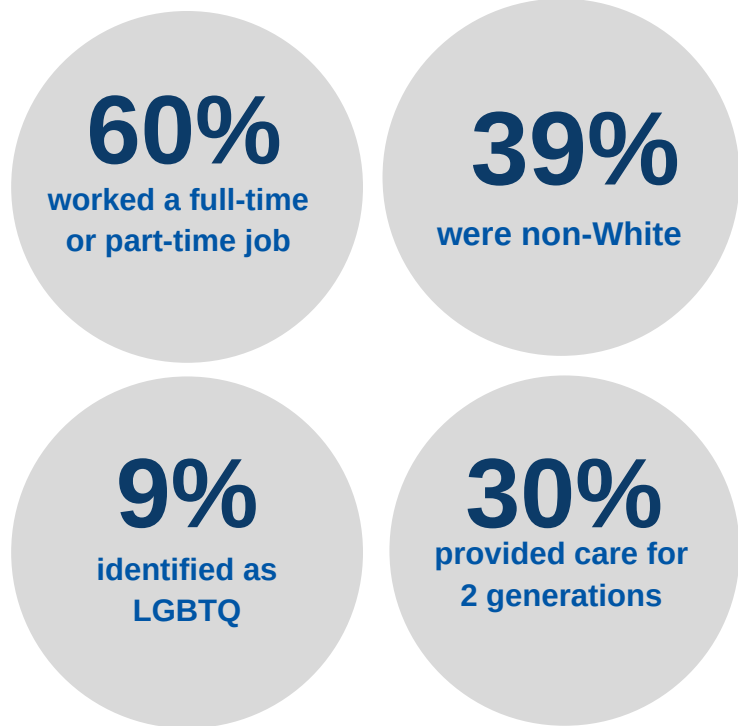
1) PHI. "Direct Care Workers in the United States: Key Facts, 2023."

2) NC Department of Health and Human Services & NC Chamber of Commerce. "Investing in North Carolina's Caregiving Workforce: Recommendations to strengthen North Carolina's nursing, direct care, and behavioral health workforce, January 2024."

Informal Caregiving

Informal caregivers include any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition.¹

In 2021, among family caregivers in the United States:²



U.S. **women** provide **2.2 times** more unpaid informal caregiving on a time-per-day basis relative to **men**.³

North Carolina (2021 Estimates):
1,280,000 family caregivers
provided
1,190,000 hours
of unpaid family care.¹

1) Family Caregiver Alliance. "Definitions."

2) Schulz R, Thompkins TA. "Informal Caregivers in the United States: Prevalence, Caregiver Characteristics, and Ability to Provide Care."

4) AARP. "Valuing the Invaluable 2023 Update: Strengthening Supports for Family Caregivers."

5) Charmes J. "The unpaid care work and the labour market: an analysis of time use data based on the latest world compilation of time-use surveys."



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