Washington State Institute for Public Policy

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Traumatic Brain Injury and Long-Term Services and Supports in Washington State

In 2023, the Washington State Legislature directed the Washington State Institute for Public Policy (WSIPP) to examine the potential need for developing specialized long-term services and supports (LTSS) for adults with traumatic brain injury (TBI).

WSIPP was directed to examine industry standards and methods states are using to provide LTSS to adults who have sustained a TBI. In addition, the assignment required an examination of the demographic characteristics of adults with a TBI in Washington (see Exhibit 1 for full directive).

In Section I, we provide background on TBI and the value of LTSS to address chronic health issues related to TBI. In Sections II and III, we describe the role of Medicaid in financing LTSS, the eligibility criteria to access Medicaid LTSS, and review the statutory authorities states use to deliver Medicaid LTSS.

In Section IV, we review the services and facilities states use to deliver LTSS to adults with TBI. In Section V, we summarize conclusions about industry standards. In Section VI, we document the incidence, demographics, and healthcare utilization outcomes of adults in Washington after a TBI. Section VII provides a conclusion and summary of this work.

Summary

Long-term services and supports (LTSS) include a range of resources to help people with chronic conditions maintain their quality of life. These services can be adapted to meet the specific needs of adults who have sustained a traumatic brain injury (TBI).

We conducted a review of Medicaid programs states use to provide LTSS. Programs that specifically target adults with brain injury are more likely to offer employment and behavioral support. Facility-based services are commonly provided in group home settings and may specify transitional or lifelong support goals. Many states integrate participant self-direction into communitybased TBI services. Several states are carefully integrating adults with complex chronic conditions, such as TBI, into managed LTSS.

We used administrative data to estimate the incidence of TBI in Washington, demographics of adults with TBIs, and healthcare outcomes. Older adults are most vulnerable to TBIs, but younger adults represent a large proportion of total injuries. Medicaid-insured adults are hospitalized for TBI at a higher rate than privately insured adults. Privately insured adults account for a larger proportion of TBIs diagnosed in outpatient settings. Rates vary across counties but are not correlated with rurality at that scale.

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Exhibit 1

Legislative Assignment

Sec. 609(4)(c)

(i) \$240,000 of the amounts in fiscal year 2024 and \$240,000 of the amounts in fiscal year 2025 are provided solely for the Washington state institute for public policy, in consultation with the Washington traumatic brain injury strategic partnership advisory council, to study the potential need for developing specialized long-term services and supports for adults with traumatic brain injuries.

(ii) At a minimum, the study must include an examination of:

- A. The demographics of adults with traumatic brain injuries in the state who are anticipated to be in need of long-term services and supports, including an examination of those who are likely to be eligible for Medicaid long-term services and supports;
- *B.* The industry standards of providing long-term care services and supports to individuals with traumatic brain injuries; and
- C. The methods other states are utilizing to provide long-term services and supports to individuals with traumatic brain injuries, including identifying the rates paid for these services and a description of any specialized facilities established to deliver these services.

(iii) A report of the findings of this study and any recommendations for increasing access to appropriate longterm services and supports for individuals with traumatic brain injuries shall be submitted to the governor and the appropriate committees of the legislature no later than June 30, 2025.

Engrossed Substitute Senate bill 5187, Chapter 475, Laws of 2023

I. Traumatic Brain Injury and Long-Term Supports

In this section, we define TBI, describe the role of LTSS in helping people manage outcomes related to their TBI, and discuss the potential harm resulting from gaps in access to long-term support.

Traumatic Brain Injury

A TBI is a change in brain function caused by an "external force."¹ The external force such as a blunt or penetrating impact or abrupt acceleration or deceleration—can cause the brain to move internally, leading to swelling, bleeding, inflammation, and other conditions that interrupt brain function and cause damage.

Harm to the brain resulting from traumatic injury occurs in two stages. After "primary" damage to the brain tissue, a "secondary" *biochemical* injury occurs over hours and days as the brain and body react to the trauma. Successful management of the secondary injury can influence whether a person experiences long-term health problems after their TBI.² Traumatic brain injuries are the most common type of "acquired" brain injury (ABI). Acquired brain injuries also include internal injuries, such as stroke, tumors, and conditions that deprive the brain of oxygen.³

Causes and Severity

The most common causes of TBI in the United States (U.S.) are sports-related injuries, interpersonal physical violence, motor vehicle crashes, falls, and proximity to explosions.⁴ These events can cause TBIs that vary in nature and severity. A widely used severity scale for TBIs has three levels, with moderate and severe TBIs typically contrasted with mild injuries in terms of potential impact on long-term cognitive and physical functioning (Exhibit 2).⁵

While helpful, a very simple scale has limitations. Individuals in the same severity category differ in important and often unknown ways, leading to differences in long-term outcomes.⁶ As many as half of the people who sustain a "mild" TBI experience fatigue and headaches one year after their injury.⁷

- ² Bramlett, H., & Dietrich, W. (2015). Long-term consequences of traumatic brain injury: Current status of potential mechanisms of injury and neurological
- outcomes. Journal of Neurotrauma, 32(23), 1834-1848. ³ Menon, D. & Bryant, C. (2019). Time for change in acquired brain injury. The Lancet Neurology, 18(1), 28.

¹ Menon, D., Schwab, D. Wright, D., & Maas, A. (2010). Position statement: Definition of traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 91(11), 1637-1640.

⁴ National Institute of Neurological Disorders and Stroke. (2024). Traumatic brain injury.

 ⁵ Teasdale, G., Maas, A., Lecky, F., . . . Murray, G. (2014). The Glasgow Coma Scale at 40 years: Standing the test of time. *The Lancet Neurology*, *13*(8), 844-854.
 ⁶ Covington, N., & Duff, M. (2021). Heterogeneity is a

hallmark of traumatic brain injury, not a limitation: a new perspective on study design in rehabilitation research. *American journal of speech-language pathology*, *30*(2S), 974-985.

⁷ Nelson, L., Temkin, N., Dikmen, S., Barber, J., Giacino, J., Yuh, E., ... & TRACK-TBI Investigators. (2019). Recovery after mild traumatic brain injury in patients presenting to US level I trauma centers: a transforming research and clinical knowledge in traumatic brain injury (TRACK-TBI) study. *JAMA neurology*, 76(9), 1049-1059.

In contrast, many individuals with a "severe" condition who receive appropriate care exhibit improvements over time.

These differences in outcomes are related to the health condition of the individual before the injury, the specific characteristics of the injury, and the quality of acute care, subacute rehabilitation, and long-term support they receive.

TBI Epidemiology

Healthcare data, such as hospital discharge records, are used to estimate how many cases of a disease occur in a population.

Exhibit 2

Severity of a TBI

Mild TBI: Sarah collides with another soccer player and hits her head. She feels dizzy and leaves the game. Sarah has does not seek professional care. Her headache resolves slowly over the next week.

Moderate TBI: Juan slipped on the stairs and hit his head. He is disoriented for several hours and receives an imaging scan in the emergency department. Juan is kept overnight for observation.

Severe TBI: Sam is found unconscious at the scene of a motor-vehicle crash and transported to a hospital. A scan shows a large buildup of blood inside their skull. Sam receives surgery and remains unconscious for several days. They are discharged to an inpatient rehab facility.

However, it is difficult to estimate how many people sustain a TBI. People who experience a moderate or severe head injury may be transported directly to the hospital, but a larger, unknown number of people do not realize they have been injured or rely on informal care. As a result, the number of TBIs that occur is underestimated.⁸

The Centers for Disease Control and Prevention maintain a TBI surveillance program. They estimate there were 1.23 million TBI-related deaths in the U.S. between 1999 and 2020 (60,000 to 70,000 per year).⁹

Nonetheless, fatal outcomes do not fully capture the burden related to TBI. Census surveys suggest that up to ten million adults—3.3% of the population—suffer a TBI each year.¹⁰

Long-term Health Outcomes

Many people who experience a TBI recover fully within days or weeks, but population-based surveys suggest that over 3% of U.S. adults live with a functional disability related to a past brain injury.¹¹ This statistic suggests that as many as 180,000 adults in Washington are impacted.

Long-term health outcomes related to TBI vary between people and over time. A study that reviewed research on "chronic TBI" years after an injury noted that five long-term health trajectories were more regularly described (Exhibit 3).¹²

⁸ Dams-O'Connor, K., Juengst, S., Bogner, J., Chiaravalloti, N., Corrigan, J., Giacino, J., . . . Hammond, F. (2023). Traumatic brain injury as a chronic disease: insights from the United States traumatic brain injury model systems research program. *The Lancet Neurology*, *22*(6), 517-528.
⁹ Shaik, N., Law, C., Elser, H., & Schneider, A. (2024). Trends in traumatic brain injury mortality in the US. *JAMA Neurology*, *81*(2), 194-195.

 ¹⁰ Waltzman, D., Black, L., Daugherty, J., Peterson, A., & Zablotsky, B. (2025). Prevalence of traumatic brain injury among adults and children. *Ann of Epidemiology*, *103*, 40-47.
 ¹¹ Schneider, A., Wang, D., Gottesman, R., & Selvin, E. (2021). Prevalence of disability associated with head injury with loss of consciousness in adults in the United States: a population-based study. *Neurology*, *97*(2), e124-e135.

¹² Pugh, M., Kennedy, E., Prager, E., Humpherys, J., Dams-O'Connor, K., Hack, D., . . . Lumba-Brown, A. (2021).

Functional and Cognitive Impairment

Rehabilitation during the first year after debilitating TBI is intended to support recovery of self-care routines and skills. This period is associated with declines in mental health, including increased anxiety, posttraumatic stress, and major depressive disorders.¹³

Exhibit 3

Common Health Profiles Years After a TBI

- Mostly recovered: mild or short-term symptoms; functioning is similar to that of people without TBI.
- 2) Mild ongoing issues: generally doing well, but with some lingering symptoms or subtle decline in health.
- 3) Physical and cognitive symptoms: ongoing problems like pain, fatigue, headaches, balance issues, or trouble thinking clearly. Accompanied by functional barriers related to self-care.
- 4) Mental health challenges: persistent issues such as depression, posttraumatic stress disorder, substance use, or emotional regulation problems, often linked to a more severe injury.
- 5) Mixed and complex injuries: a combination of physical, cognitive, and mental health challenges related to categories three and four, which affect life in many ways.

Notes:

These categories are descriptive summaries of TBI phenotypes reported in Pugh et al. (2021).

Phenotyping the spectrum of traumatic brain injury: a review and pathway to standardization. *Journal of*

Neurotrauma, 38(23), 3222-3234.

 ¹³ Ponsford, J., Alway, Y., & Gould, K. (2018). Epidemiology and natural history of psychiatric disorders after TBI. *Journal of Neuropsychiatry and Clinical Neurosciences*, *30*(4), 262-270.
 ¹⁴ McCrea, M., Giacino, J., Barber, J., Temkin, N., Nelson, L., Levin, H., ... & TRACK-TBI Investigators. (2021). Functional outcomes over the first year after moderate to severe traumatic brain injury in the prospective, longitudinal TRACK-TBI study. *JAMA Neurology*, *78*(8), 982-992.

¹⁵ Corrigan, J., Cuthbert, J., Harrison-Felix, C., Whiteneck, G., Bell, J., Miller, A., . . . Pretz, C. (2014). US population estimates Recent research has demonstrated the difficulty of predicting rehabilitation trajectories for a given individual. While 90% of individuals who experience a severe TBI require high-level care and support with activities of daily living (such as toileting, eating, and dressing) in the first month after an injury, up to half may recover independence at home over the first year.¹⁴

Risk of Death in the Years After a TBI

Individuals who sustain a TBI have an increased risk of premature death. Since these outcomes occur years after an injury, their potential connection to a TBI may be ignored or misunderstood.

In a study of individuals who received acute inpatient care, 20% died within five years, and more than 50% were moderately to severely disabled.¹⁵ People who are older at the time of their injury and who are discharged from a hospital in worse condition have worse long-term outcomes.¹⁶

Common causes of death in this population are neurological (e.g., seizures), systemic (e.g., sepsis, pneumonia, cardiovascular disease), and behavioral (e.g., accidental poisoning, vehicle crashes).¹⁷

of health and social outcomes 5 years after rehabilitation for traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, *29*(6), E1-E9.

¹⁶ Wilson, L., Stewart, W., Dams-O'Connor, K., Diaz-Arrastia, R., Horton, L., Menon, D., & Polinder, S. (2017). The chronic and evolving neurological consequences of traumatic brain injury. *The Lancet Neurology*, *16*(10), 813-825.

¹⁷ Harrison-Felix, C., Pretz, C., Hammond, F. M., Cuthbert, J. P., Bell, J., Corrigan, J., . . . Haarbauer-Krupa, J. (2015). Life expectancy after inpatient rehabilitation for traumatic brain injury in the United States. *Journal of Neurotrauma*, *32*(23), 1893-1901.

Many adults who sustain a mild brain injury do not have traditional "risk factors" (such as old age), do not receive a medical diagnosis, and live with unidentified and poorly managed symptoms.¹⁸

These conditions can also contribute to premature mortality. In one prospective study of younger adults with mild brain injuries (median age of 39 years), more than one-third died within 15 years, and victims suffered additional brain injuries at a rate 19 times greater than a comparison group.¹⁹

Long-term Health Outcomes

Sustaining a TBI is associated with neurodegenerative diseases such as Alzheimer's, dementia, and stroke.²⁰ Recent research has drawn attention to the impact of repeated mild TBIs on the risk of these outcomes.²¹

A brain injury can both cause and accelerate diseases in other organs. Studies suggest that head trauma is associated with double the risks of cardiovascular (e.g., coronary heart disease) and endocrine disorders (e.g., diabetes) over the first ten years.²²

It is not certain if these long-term outcomes are caused by a TBI or are simply more common among people who experience a TBI. Explanations for long-term health outcomes due to a TBI are biological, such as immune and metabolic responses to secondary brain injury (i.e., inflammation), as well as social, such as the impacts of TBI on community integration, work, and income.²³

Long-term Support for Chronic TBI

The evidence about the long-term impacts of TBIs has shifted medical and policymaking attention towards strategies to manage long-term symptoms related to brain injury, including developing LTSS appropriate for this population.

Long-term Services and Support (LTSS)

LTSS are social and health services provided to individuals with decreased capacity for mental health conditions.²⁴ These services are differentiated from acute, post-acute, and sub-acute care in terms of goals, setting, and duration of care (Exhibit 4).²⁵

A study of the scope of long-term supports needed by people who experienced a TBI concluded that the type of supports "varied widely," including 23 out of 24 possible items from a validated LTSS-needs scale.²⁶

¹⁸ Wilson et al. (2017).

¹⁹ McMillan, T., Weir, C., & Wainman-Lefley, J. (2014). Mortality and morbidity 15 years after hospital admission with mild head injury: a prospective case-controlled population study. *Journal of Neurology, Neurosurgery & Psychiatry*, 85(11), 1214-1220.

²⁰ Wilson et al. (2017).

²¹ Wilson et al. (2017).

²² Izzy, S., Chen, P., Tahir, Z., Grashow, R., Radmanesh, F., Cote, D., . . . Zafonte, R. (2022). Association of traumatic brain injury with the risk of developing chronic cardiovascular, endocrine, neurological, and psychiatric disorders. *JAMA Network Open*, *5*(4), e229478-e229478.

²³ Masel, B., & DeWitt, D. (2010). Traumatic brain injury: a disease process, not an event. *Journal of Neurotrauma*, *27*(8), 1529-1540.

²⁴ Colello, K. (2023). *Long-rerm services and supports: History of federal policy and programs*. Congressional Research Service. R47881.

²⁵ Wang, Y., Chou, M., Liang, C., Peng, L., Chen, L, & Loh, C. (2019). Post-acute care as a key component in a healthcare system for older adults. *Annals of Geriatric Medicine and Research*, *23*(2), 54.

²⁶ Tate, R., Lane-Brown, A., Myles, B., & Cameron, I. (2020). A longitudinal study of support needs after severe traumatic brain injury. *Brain Injury*, *34*(8), 991-1000.

	Acute care	Post-acute care	Sub-acute care	LTSS
Goal	Life-saving intervention, medical stabilization	High-intensity therapy to support functional recovery	Medical oversight, rehabilitation at a lower intensity	Functional support, behavioral health, long-term stability
Setting	Hospital intensive care unit, emergency department	Rehabilitation facility (inpatient or outpatient)	Skilled nursing facility, transitional care facility, private home	Private home, community-based supported living facility
Duration	Hours to weeks	Weeks to months	Months	Ongoing, potentially lifelong

Exhibit 4 Stages of Care Following a TBI

Note:

The distinction between "post-acute" and "sub-acute" care is taken from Wang et al. (2019).

For example, LTSS for TBI include high-level support with feeding and continence; assistance with activities of daily living (e.g., chores, medication use); and services for self-care due to a physical, cognitive, or aim to improve quality of life. Examples of selfcare services include counseling, emotional support, and practical assistance in managing relationships in the context of new functional challenges.

Health and social conditions related to these needs may appear and persist unpredictably for many years.²⁷ Even relative to other chronic illnesses, this type of variation between people and over time, increases the value of ongoing, tailored support.²⁸

LTSS Settings

LTSS can be provided by caregivers, with and without formal training, in private and groupliving environments. Researchers estimate that as much as three-quarters of LTSS in the U.S. is unpaid care provided by family and friends.²⁹ Paid and *formal* long-term services can be provided in both "institutions," such as nursing facilities, as well as "non-institutional" assisted living facilities and private homes.

Unlike post-acute or sub-acute care, which supports medical stabilization, recovery, and rehabilitation (Exhibit 4), LTSS aims to help an individual maintain a desired level of self-care, independence, and quality of life while living with a chronic health condition.³⁰

²⁷ Masel & DeWitt (2010).

²⁸ Heiden, S., & Caldwell, B. (2018). Considerations for developing chronic care system for traumatic brain injury based on comparisons of cancer survivorship and diabetes management care. *Ergonomics*, *61*(1), 134-147.

 ²⁹ Thomas, K., & Applebaum, R. (2015). Long-term services and supports (LTSS): A growing challenge for an aging America. *Public Policy & Aging Report, 25*(2), 56-62.
 ³⁰ Colello, K. (2023)

Since the passage of the 1990 Americans with Disabilities Act, recognition of this goal has led to a "rebalancing" of the US LTSS industry away from expensive and isolating institutional (i.e., nursing facility) care towards home and community-based services (HCBS). Of federal LTSS spending in 1995, 82% was on institutional services, but spending on HCBS has exceeded institutional care since 2013.³¹

In 2014, the federal Centers for Medicare & Medicaid Services (CMS) issued a rule establishing enforceable federal standards for HCBS settings.³² The requirements of the rule took effect in 2023.³³ This regulation provided guidelines for categorizing and describing HCBS.³⁴ The most common categories of HCBS for people with brain injuries are listed in Exhibit 5.³⁵

Consequences of Unmet Need

Access to appropriate LTSS can affect whether individuals who sustain a TBI experience social and health complications and the extent to which family members bear the burden of caregiving.

Health Outcomes of Unmet Need

Adults with disabilities who do not receive professional LTSS are more likely to go without eating, bathing, or dressing and have decreased mobility, such as staying in bed or never leaving home.³⁶

Exhibit 5

Most Common HCBS for Brain Injury

Home-based services: personal care and basic health services that help an individual remain in their home.

Equipment, technology, and modifications: tools that help people live safely and independently at home, such as ramps and emergency response systems.

Health and therapeutic services: supports that help people manage chronic conditions, such as medication management, physical therapy, and health status monitoring.

Supported employment: services which help people find and keep a job, including job coaching and career planning.

Caregiver support: training and support for people who care for an individual who sustained a TBI, such as "respite" care.

Day services: structured activities for adults with disabilities which promote skill-development and social interaction.

Gaps in receipt of care after TBI can lead to poor health outcomes such as medication errors, secondary falls and injuries, and preventable conditions such as pneumonia and urinary tract infections.³⁷

³¹ Medicaid and CHIP Payment and Access Commission (MACPAC). (2019). Twenty Years Later: Implications of Olmstead v. L.C. on Medicaid's Role in Providing Long-Term Services and Supports. Issue Brief.

 ³² Centers for Medicare & Medicaid Services (2014). Final Rule Fact Sheet: Home and Community Based Services.
 ³³ Mohamed, M., Burns, A., & Watts, M. (2023). How are states implementing new requirements for Medicaid homeand community-based services? KFF.

³⁴ Centers for Medicare & Medicaid Services (2014). Medicaid Home and Community-Based Services (HCBS) Taxonomy Category and Subcategory Definitions.

³⁵ Medicaid and CHIP Payment and Access Commission (MACPAC). (2023). Access to Home- and Community-Based Services. Table 4A-3.

³⁶ Allen, S., Piette, E., & Mor, V. (2014). The adverse consequences of unmet need among older persons living in the community; dual-eligible versus Medicare-only beneficiaries. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 69(7), S51-S58.

³⁷ Sharma, R., Shultz, S., Robinson, M., Belli, A., Hibbs, M., O'Brien, T., & Semple, B. (2019). Infections after a traumatic brain injury: The complex interplay between the immune and neurological systems. *Brain, behavior, and immun,* 79, 63-74.

These avoidable outcomes contribute to emergency department visits and hospitalization at public cost.³⁸

Behavioral Outcomes of Unmet Need

People recovering from brain injury are at risk of issues with emotional regulation, particularly when services are poorly integrated (such as a lack of collaboration between case management, primary care, and substance use treatment providers).³⁹

In one sample of individuals with severe TBIs, the reported need for psychosocial support was nearly universal over the first three years following injury.⁴⁰ The combination of substance use and poor mental health, including complications with post-traumatic stress disorder, can result in challenging behaviors, increasing the need for professional specialist services.⁴¹

Financial Outcomes of Unmet Need

Family caregivers often incur social costs (such as loss of full-time work) to provide care. Women are particularly likely to leave the workforce, decrease their hours worked, and receive lower wages after assuming care for an adult family member.⁴² Household spending to support caregiving is considerable. Family caregivers report the difficulty of financial planning when medical professionals cannot provide long-term prognoses.⁴³ Limited coverage of specialist services by private long-term care insurance contributes to financial barriers to continuing treatment.⁴⁴ As a result, out-ofpocket costs to access long-term support exceed the costs of acute care.⁴⁵

Summary of Section I

Adults who have sustained a TBI often need long-term support to address chronic health symptoms related to their injury. These services commonly support social and functional needs, rather than ongoing medical treatment, and are increasingly delivered in home and community-based settings. These industry standards were codified by the Americans with Disabilities Act (1990), Supreme Court decision *Olmstead v. L.C.* (1999), and the CMS HCBS final rule (2014). Inadequate access to professional LTSS can lead to adverse health outcomes, behavioral challenges, and household financial strain.

 ³⁸ Hass, Z., DePalma, G., Craig, B., Xu, H., & Sands, L. (2017).
 Unmet need for help with activities of daily living disabilities and emergency department admissions among older
 Medicare recipients. *The Gerontologist*, *57*(2), 206-210.
 ³⁹ Chan, V., Toccalino, D., Omar, S., Shah, R., Colantonio, A. (2022). A systematic review on integrated care for traumatic brain injury, mental health, and substance use. *PLoS One*, *17*(3), e0264116.

⁴⁰ Tate, R., Lane-Brown, A., Myles, B., & Cameron, I. (2020). A longitudinal study of support needs after severe traumatic brain injury. *Brain Injury*, *34*(8), 991-1000.

⁴¹ Simpson, G., Sabaz, M., Daher, M., Gordon, R., & Strettles, B. (2014). Challenging behaviours, co-morbidities, service utilisation and service access among community-dwelling adults with severe traumatic brain injury: a multicentre study. *Brain Impairment*, *15*(1), 28-42.

⁴² Van Houtven, C., Coe, N., & Skira, M. (2013). The effect of informal care on work and wages. *Journal of Health Economics*, *32*(1), 240-252.

⁴³ Kreitzer, N., Bakas, T., Kurowski, B., Lindsell, C., Ferioli, S., Foreman, B., . . . Adeoye, O. (2023). The experience of caregivers following a moderate to severe traumatic brain injury requiring ICU admission. *The Journal of Head Trauma Rehabilitation*, *35*(3), E299-E309.

 ⁴⁴ Dams-O'Connor, K., Landau, A., Hoffman, J., & St De Lore, J. (2018). Patient perspectives on quality and access to healthcare after brain injury. *Brain Injury*, *32*(4), 431-441.
 ⁴⁵ Ponsford, J. L., Spitz, G., Cromarty, F., Gifford, D., & Attwood, D. (2013). Costs of care after traumatic brain injury. *Journal of Neurotrauma*, *30*(17), 1498-1505.

II. Medicaid long-term Services

In this section, we describe the central role of Medicaid in delivering LTSS in the U.S.

Medicaid is the primary U.S. payer for LTSS. To receive federal subsidization for a Medicaid program, states must comply with rules related to delivering Medicaid services (Exhibit 6). Beyond these base requirements, states have control over the scope and goals of their Medicaid spending.

How states design their Medicaid programs—such as choosing eligibility criteria and provider reimbursement models—are fundamental state-level policy decisions that impact access to LTSS among adults who have sustained a TBI.

Medicaid-financed LTSS

More than 60% of spending on LTSS in the U.S. (\$415 billion in 2022) is paid by Medicaid.⁴⁶ Medicare is not considered a payer for LTSS since it only covers up to 100 days of sub-acute care in a skilled nursing facility, with co-insurance, after a qualifying hospital stay.⁴⁷ In 2025, the federal government formally designated TBI as a Medicare "chronic condition," making Medicare enrollees with a TBI eligible for a "Special-Needs Plan" and expedited access to Medicaid LTSS.⁴⁸

Exhibit 6

Medicaid

Medicaid is the U.S. public health insurance program for groups historically excluded from the private health insurance marketplace, such as low-income aged and disabled persons.

Medicaid is **subsidized** by the federal government and administered by states. The proportion of Medicaid spending that is subsidized depends on state income and currently ranges from 50% (e.g., Washington and high-income states) to 77% (Mississippi).

To receive federal funding, states must develop a Medicaid **state plan**, which organizes the delivery of services to their Medicaid-eligible population.

State plan services must be:

- 1) Sufficient to meet targeted needs
- 2) Comparable across groups
- 3) Offered *statewide*
- Offer beneficiaries a *choice* of providers

States have control over:

- Services to offer participants
- Eligibility criteria for services
- Facilities to deliver services
- Required provider qualifications
- Reimbursement to providers

⁴⁶ Chidambaram, P., & Burns, A. (2024). 10 things about LTSS. KFF.

⁴⁷ Centers for Medicare & Medicaid Services (2024). *Medicare learning network newsletter*. Weekly Edition.

⁴⁸ Center for Medicare & Medicaid Services. *Special Needs Plans (SNP)*.

The proportion of LTSS attributed to out-ofpocket spending is substantial (17%), while spending by the Veterans Health Administration (2%)⁴⁹ and other payers (including private long-term care insurance) (19%)⁵⁰ has decreased over the last decade with increases in private insurance LTSS premiums, limits on the duration of services,⁵¹ and enrollment of veterans in Medicaid to access HCBS.⁵²

Financial Eligibility for Medicaid LTSS

There are three ways to qualify financially for Medicaid LTSS. First, low-income individuals who have a qualifying "categorical" need (e.g., people with disabilities) may qualify as "categorically needy." Second, most states allow individuals to qualify as "medically needy" if they have a health-related need but have income or assets exceeding categorical limits. Third, almost all states allow individuals with disabilities to qualify if they can and want to continue working.

Categorically Needy. For a low-income person whose income qualified them for Medicaid before their injury, the most general route to Medicaid LTSS after a TBI is through establishing "categorical" need as "aged, blind, or disabled."

Most states, including Washington, use federal eligibility requirements to receive Supplemental Security Income (SSI) as their criteria for establishing whether a person qualifies as categorically needy based on a disability.⁵³ Federal SSI criteria include both financial and functional assessments. In addition to asset (\$2,000) and income limits (\$967/month),⁵⁴ disability-based SSI is accessible to adults who cannot "engage in any substantial gainful activity [due to a] medically determinable [...] impairment which can be expected to result in death or [...] last for a continuous period of [...] 12 months."⁵⁵

Some health conditions, such as spinal cord injury, make a person automatically eligible for SSI. Individuals with TBI must demonstrate either "disorganized" motor function or "marked limitation in physical functioning" for at least three months following injury.⁵⁶ Given that many functional outcomes can improve during the first months after an injury, this process can delay access to care for critical intervals.⁵⁷

In Washington, the Medicaid state plan (called "Apple Health") maintains several programs that expedite the receipt of services while financial eligibility is being determined (e.g., "Fast Track" and "Presumptive Eligibility").⁵⁸

⁵⁰ Including spending by the Children's Health Insurance Program (CHIP), the Veterans Health Administration (VA), Indian Health Services, and state and other programs.

⁵¹ Rau, J., & Aleccia, J. (2023). *Why long-term care insurance falls short for so many*. KFF Health News.

Medicaid-eligible. MACPAC. (2023). *MACStats: Medicaid and CHIP data book. Section 4: Medicaid & CHIP Eligibility. 104.* ⁵⁴ Washington State Health Care Authority. (2025). *Washington Apple Health Income and Resource Standards.* 10-00096.

Rehabilitation, 86(5), 905-911. ⁵⁸ Washington State Health Care Authority. (2024).

⁴⁹ Colello, K., & Sorenson, I. (2023). *Who pays for long-term services and supports?* Congressional Research Service. IF 10343.

⁵² Colello, K., & Viranga Panangala, S. (2017). *Long-Term Care Services for Veterans*. Congressional Research Service. R44697.

⁵³ Eight "209(b)" states use more restrictive income and asset requirements than SSI but are required to offer alternative pathways for "medically needy" persons to become

⁵⁵ Social Security Administration. (n.d.). *Disability evaluation under Social Security*.

⁵⁶ Social Security Act Section 11.18. Traumatic Brain Injury.

⁵⁷ Wei, W., Sambamoorthi, U., Crystal, S., & Findley, P. (2005). Mental illness, traumatic brain injury, and Medicaid expenditures. *Archives of Physical Medicine and*

Presumptive eligibility for Home and Community Services.

Medically Needy. As of 2022, 32 states, including Washington, offered a "medically needy pathway" to Medicaid for older adults and people with disabilities.⁵⁹ Medically needy enrollees have a condition that would make them categorically needy, except that their assets are above the limit. A privately insured person might pursue this pathway after exhausting private long-term care insurance.

Most states require that medically needy individuals liquidate or *spend down* their assets on medical expenses before Medicaid coverage begins. If an enrollee meets functional eligibility criteria for LTSS, they benefit from a "Special Income Rule" with a higher income threshold equal to 300% of the SSI benefit (\$2,901 per month in 2025).

Workers with Disabilities. Forty-seven states, including Washington, offer a "buy-in pathway" to categorically needy coverage to adults with disabilities who can maintain employment. These programs usually do not have asset or income limits, but the enrollee must pay a portion (capped at 7.5%) of their income as a premium. Six states (MA, MD, MN, NJ, RI, and WA) do not have an income ceiling for eligibility.⁶⁰

⁵⁹ Musumeci, M., O'Malley, M., Ammula, M., & Burns, A.
 (2022). KFF. *Medicaid financial eligibility pathways based on old age or disability in 2022: Findings from a 50-state survey.* ⁶⁰ KFF (2025). *Medicaid eligibility through buy-in programs for working people with disabilities.*

Functional Eligibility for Medicaid LTSS

Functional eligibility for Medicaid LTSS is based on a beneficiary's "level of care" (LOC) needs. Federal law requires that Medicaid enrollees who need an "institutional" level of care qualify for LTSS, but there is no federal definition of "institutional."⁶¹ Across states, the standard functional requirement for LTSS is a "nursing facility LOC."

States create and use their own assessment survey tools to establish whether an enrollee requires a nursing facility LOC. Across states, LOC assessment tools include questions about whether an individual needs support for activities of daily living (e.g., bathing), mental health, clinical care (e.g., use of medications), home environment (e.g., access to appliances), and social circumstances.⁶²

Reimbursement to Providers

State Medicaid programs make payments to healthcare providers using fee-for-service (FFS) or managed care systems.

In FFS Medicaid, the state pays healthcare providers for each service delivered to beneficiaries. In a managed care system, the state contracts with a managed care organization (MCO) to reimburse providers. The state pays the MCO a fixed monthly sum to cover the cost of providing necessary services for each covered member. This payment model shifts financial risk from the state to the MCO.

⁶¹ Colello, K., & Morton, W. (2019). *Medicaid eligibility: older adults and individuals with disabilities*. Congressional Research Service. R46111.

⁶² Medicaid and CHIP Payment and Access Commission (MACPAC). (2016). *June 2016 Report to Congress on Medicaid and CHIP*. Chapter 4: Functional Assessments for Long-Term Services and Supports. pp. 67-83.

Goals of managed care include controlling costs (e.g., by allowing the MCO to manage the use of care through the selection of provider networks and preauthorization of selected services) and improving quality for members (e.g., by providing MCOs financial incentives to meet health and patient satisfaction benchmarks).⁶³

Historically, managed care was used for healthier and lower-cost populations, but states increasingly use *managed LTSS* (MLTSS) to provide services to groups with more significant and costly needs.

A documented concern of MLTSS is that profit-motivated MCOs may restrict access to necessary services for populations with complex conditions.⁶⁴ The federal government has developed guidelines to assist states during negotiations with MCOs, such as ensuring that monthly payments are high enough to achieve health goals and recommending processes to evaluate changes in service-use outcomes.⁶⁵

As of 2024, 42 states use an MCO to provide some services to their Medicaid beneficiaries.⁶⁶ In 2022, 4.5% of Washington's LTSS spending was to an MCO, primarily related to the provision of behavioral health services. Six states do not use managed care (AK, CT, ME, MT, SD, and WY), while 96% of LTSS spending in Iowa was to an MCO (Exhibit 7).

Summary of Section II

For most U.S. adults, HCBS are subsidized by the federal government through Medicaid. Private insurers and the VA offer some HCBS for limited durations or under specific conditions but are not major sources of long-term coverage. States administer their own Medicaid programs, leading to wide variation in the methods used to deliver LTSS, including the type of services available to beneficiaries, as well as functional and financial eligibility criteria for accessing support. Approaches to reimburse providers also differ: some states exclusively use feefor-service, while others have integrated their LTSS into managed care systems.

⁶³ Centers for Medicare & Medicaid Services. 42 CFR Parts 430, 438, and 457. (2024). *Medicaid Program, Managed Care Access, Finance, and Quality*.

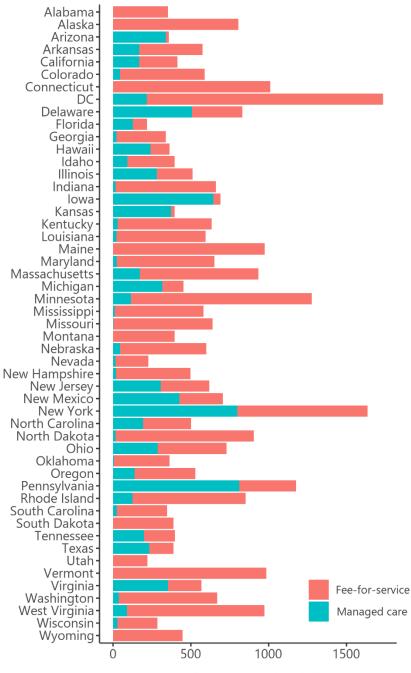
 ⁶⁴ Wysocki, A., Libersky, J., Gellar, J., Liu, S., & Pearse, M.
 (2019). *Managed Long-Term Services and Supports evaluation design plan update*. Mathematica Policy Research.

⁶⁵ Center for Medicare & Medicaid Services. (n.d.) *Managed Long-Term Services and Supports*.
⁶⁶ Hinton, E. & Raphael, J. (2025). *10 things to know about*

Minton, E. & Raphael, J. (2025). To things to know about Medicaid Managed Care. KFF.

Exhibit 7

State LTSS Expenditures (2022) by Fee-For-Service and Managed Care



LTSS expenditures per capita (dollars, 2022)

Notes:

Data are from the Centers for Medicare & Medicaid Services, Long Term Services and Supports, Reports & Evaluations, Long Term Services and Supports Users and Expenditures (Data Tables, 2022). A2_LTSSExpDlvrySystm_2022, Sheet A.2.10 System-Dist. Total cost standardized as per capita cost by decennial census population estimates.

III. Methods States Use to Provide Medicaid LTSS

In this section, we review the programs that states use to offer LTSS and describe how these programs are implemented in Washington. We begin by reviewing LTSS generally, as adults with TBI in many states rely on broader, non-targeted services.

Medicaid LTSS

States must comply with core federal Medicaid requirements but have opportunities to develop their own systems and processes to deliver services.

The federal government requires that states provide some *mandatory* LTSS and offers states a list of additional *optional* services they can choose to provide. Further, amendments to the Social Security Act (SSA) allow states to waive core Medicaid requirements—such as state-wide coverage—and offer tailored services to targeted groups (Exhibit 8).

Required State Plan Services

Most mandatory state plan services address acute needs, such as inpatient hospital stays. The only mandatory LTSS are *institutional* Nursing Facility Services and *non-institutional* Home Health Services.

Nursing facilities are residential institutions that provide "total care," including room and board.

institutions must provide residents with medical and rehabilitation services.⁶⁷ Home Health Services are skilled nursing services and equipment sufficient to deliver medical care in a residential setting. As of 2018, 44 states, including Washington, included physical, occupational, or speech therapy services as a Home Health benefit.⁶⁸ Optional State Plan Services

Federal law specifies that long-term care

States can offer community-based LTSS as optional benefits under their Medicaid state plan. These services, which are not part of the federal HCBS benefit category,⁶⁹ include case management, Health Homes, personal care, nursing, and rehabilitative services.⁷⁰

Case management involves assisting beneficiaries as they transition from institutional to community-based care, including supporting access to other medical and social services (e.g., non-Medicaid benefits). Health homes are integrated physical and behavioral health programs. Personal care services include assistance with activities of daily living, such as laundry, meal preparation, and bathing, for individuals who do not need a nursing facility LOC. In Washington, state plan personal care services allow clients to selfdirect a personal care provider selected from a vendor contracted by the state.⁷¹ Rehabilitative services are a broad category, including therapies offered in institutional settings, as well as other services targeting mental health and substance use disorders.

^{67 42} C.F.R. (4G) §§483.1-483.95.

⁶⁸ Colello (2023).

⁶⁹ Medicaid HCBS statutory authorities include Social Security Act sections 1915(c), 1915(i), 1915(j), and 1915(k).

⁷⁰ Colello (2023).

⁷¹ Participants may *"select, schedule, supervise, direct, and dismiss"* a personal care provider. ALSTA Long-Term Care Manual, Chapter c: Medicaid Personal Care, p. 7c.8.

Exhibit 8

Medicaid Long-Term Services and Supports: Required, Optional, and Waiver Services

Medicaid LTSS vehicle	Description		Program
State plan	Federally required services that all states must cover for eligible	Nursing facility services	Institutional "total care" services
LTSS (Required)	enrollees. Focuses on institutional and skilled/medical care needs.	Home Health	Services and equipment to provide medical care in a home (non- institutional) setting
State plan LTSS (Optional)	Additional services that	Medicaid Personal Care services	Assistance with activities of daily living for clients who do not need an institutional level of care
	states may choose to offer to eligible enrollees. Includes personal care, self- directed support, and additional home and community-based services	SSA 1915(k) Community First Choice services	Home and community-based services (personal care, assistive technology, training, transition support, caregiver training) for individuals who need an institutional level of care
		SSA 1915(i) HCBS State Plan option services	HCBS for the targeted eligibility group who do not necessarily meet the institutional level of care
Waivers	Flexible regulatory tools allowing states to develop and target LTSS,	SSA 1915(c) HCBS Waivers	HCBS beyond 1915(k) for targeted individuals who would otherwise need institutional care
	often for specific populations	SSA 1115 Demonstrations	Broad experimental freedom to test new approaches to Medicaid coverage, delivery, and payment

Note: SSA 1915(i),1915(c), and 1115 allow waiving of statewide coverage and comparability requirements through the targeting process.

SSA Section 1915(k). "Community First Choice" (CFC) services include personal care, respite, habilitation, and assistive technology. Individuals receiving CFC services must demonstrate a need for a nursing facility LOC, and the state must offer the CFC option statewide, but the federal matching payment is six percentage points higher than other state plan services (56% for WA). Nine states (AK, CA, CT, MD, MT, NY, OR, TX, and WA) offer CFC services.⁷²

SSA Section 1915(i). The "State Plan HCBS Option" allows states to offer HCBS to groups with significant needs but who do not necessarily require an institutional level of care. As of 2025, researchers noted that only North Dakota uses the 1915(i) option to provide state plan HCBS to adults with TBI below the nursing facility level of care.⁷³ Many states, including Washington, require an institutional level of care to access 1915(i) services to control costs.

Waivers and Demonstrations

Amendments to the SSA provide two ways for states to deliver targeted or innovative LTSS to beneficiaries.

SSA Section 1915(c) "Waivers." 1915(c) allows states to "waive" comparability and statewide coverage requirements to provide tailored HCBS to some beneficiaries. 1915(c) "waivers" often include both health and social interventions. States have the freedom to choose, tailor, and name services according to their resources, delivery systems, and goals.⁷⁴ As of 2025, 1915(c) waivers can be designated to provide services for general groups such as *Disabled (Physical)* or one of ten subgroups, including *Brain Injury*. Most states operate several 1915(c) waivers, each providing services to a target group.

SSA Section 1115 Demonstration Waivers.

Section 1115 "demonstrations" enable states to reform their Medicaid program.⁷⁵ In contrast to 1915(c) waivers, these changes may be systemwide, such as a statewide transition to managed care. Unlike 1915(c), 1115 demonstrations are not exclusively related to LTSS. This scope means that reforms may indirectly benefit or impact individuals with brain injuries.

Choosing Between Medicaid LTSS Vehicles

Waivers and demonstrations allow for the development of targeted HCBS programs for adults with brain injuries. It is not implied, however, that the absence of a single type of program necessarily determines the quality of long-term support for adults who have sustained a TBI. As we will discuss in Section IV, some states have developed dedicated brain injury services but make those programs inaccessible through enrollment limits.

Further, while 1915(i) and 1915(k) programs have one-time approvals, 1915(c) and 1115 waivers must be renewed every five years. Since these processes can require significant administrative time and funding, some states may choose to allocate scarce resources to deliver state plan services and to improve quality.⁷⁶

⁷² Musumeci, M., O'Mally Watts, M., & Chidambaram, P. (2020). *Key state policy choices about Medicaid Home and Community-Based Services*. KFF.

⁷³ Corrigan, J., Hammond, F., Sander, A., & Kroenke, K. (2024). Recognition of traumatic brain injury as a chronic condition: A commentary. *Journal of Neurotrauma*, *41*(23-24), 2602-2605.

⁷⁴ Center for Medicare and Medicaid Services. Waiver Applications. (n.d.) 1915(c) Waiver Application & 372 Reports.

⁷⁵ Colello (2022).

⁷⁶ Albaroudi, A., & Huson, T. (2023). *Medicaid Home- and Community-Based Services: Comparing requirements for states.* Medicaid and CHIP Payment and Access Commission

Medicaid LTSS in Washington State

The Washington Health Care Authority (HCA) administers Apple Health, the Medicaid State Plan. Washington's "Home and Community Services" are administered by the Aging and Long-Term Support Administration (ALTSA).

Functional Eligibility for Apple Health LTSS.

Apple Health participants can receive LTSS while they require a nursing facility LOC. ALTSA determines this LOC need using the state's Comprehensive Assessment Reporting and Evaluation (CARE) tool.⁷⁷ CARE assesses whether a person:

- Requires a daily service [...] provided under the supervision of a registered or licensed practical nurse or
- Has multiple unmet personal care needs [...] which necessitate assistance or
- 3) Has a cognitive impairment and one unmet personal care need *or*
- Will likely need an institutional level of care within 30 days unless services are provided.⁷⁸

If an individual meets one of these criteria, ALTSA uses a second scoring tool to place recipients into a residential group.⁷⁹ Following federal requirements, ALTSA uses a "general hierarchy" that requires the use of state plan services, such as 1915(k) Community First Choice, before waiver services.⁸⁰

Apple Health Waivers.

ALTSA operates three 1915(c) waivers to provide HCBS for adults. Individuals may receive both state-plan and waiver services. The state also operates a 1115 demonstration, which has been used to develop new services for LTSS beneficiaries. Exhibit 9 describes Apple Health waivers and demonstration programs in greater detail.

Summary of Section III

States offer different LTSS through their Medicaid plans. All states must offer nursing facility and home health (medical) services in compliance with federal regulation. A minority of states, including Washington, offer a large range of HCBS to eligible adults, such as Community First Choice (CFC) services, which include assistive technology, personal care, and other supports. Further, states use Medicaid waivers and demonstrations to target services to specific populations. In Washington, the Medicaid state plan ("Apple Health") uses these methods to provide a range of LTSS. Like many other states, Apple Health offers a path for financially ineligible adults to "spend down" their resources to access care. The state determines functional eligibility for LTSS using its CARE assessment tool.

 $^{^{77}}$ WAC 388-106-0355. "Am I eligible for nursing facility services?"

⁷⁸ Washington State Department of Social and Health Services. ALTSA Long-Term Care Manual. Chapter 7b: Community First Choice (CFC).

 ⁷⁹ WAC 388-106-0115 "How does CARE use criteria place me in a classification group for residential facilities?"
 ⁸⁰ Washington State Department of Social and Health Services. ALTSA Long-Term Care Manual. Chapter 7: Intro to Medicaid, State Plan, and 1915c waivers.

Exhibit 9

Washington Apple Health 1115 and 1915(c) Programs

Law	Washington program	Description			
SSA 1915(c)	Community Options Program Entry System (COPES)	Services for individuals whose needs exceed state plan (e.g., CFC) benefits. Participants receive attendant care, training, equipment, transportation, and transition benefits in private homes, group homes, and assisted living facilities. A client with TBI is referenced in the ALTSA manual.			
		Participants enrolled per program year (2024-2028): 56,644 to 68,851			
	Residential Support Waiver (RSW)	Services for individuals whose behavioral health needs exceed other services. Eligibility criteria include currently residing at a state hospital or psychiatric unit and a history of problems managing medications or other "serious challenging behaviors" that have led to previous failure living in a community setting. Persons with TBI are identified as a priority group.			
		 Services are facility-based with four tiers: (1) Adult Family Homes (AFHs) (2) Assisted Living Facilities (ALFs) (3) Enhanced Adult Residential Care Facilities (EARCFs) (4) Enhanced Services Facilities (ESFs) 			
		Participants enrolled per program year (2024-2028): 4,357 to 6,856			
	New Freedom Waiver	Allows residents of King and Pierce Counties to self-direct personal care services, including managing a personal budget. A waiver does not prioritize the delivery o services to individuals with TBI.			
		Participants enrolled per program year (2025-2029): 675			
	Foundational Community Supports	Housing and employment services for populations with concurrent behavioral and long-term care needs. Having a TBI is one of the "Risk Factors" that confer access to this service.			
	Program	Participants enrolled (total 09/01/17 to 9/1/24): 14,365			
	State Family Caregiver Support Program	Two programs that support older members (ages 55+) who are functionally eligible or at risk but not currently receiving Medicaid LTSS.			
SSA 1115		<i>Medicaid Alternative Care (MAC):</i> Provides resources to individuals who are eligible for but not receiving LTSS to reimburse and support the work of unpaid caregivers. It does not require some LTSS financial rules (e.g., provisions related to the treatment of home equity as an asset).			
		<i>Tailored Supports for Older Adults (TSOA</i>): Benefit (respite, equipment, caregiver training) for individuals "at risk" of needing LTSS in the future but who do not meet Medicaid financial eligibility criteria.			
		Participants enrolled (period 10/1/23 to 12/31/23): 3,962			
	Presumptive eligibility (LTSS)	Program to expedite access to home and community-based LTSS while full functional and financial eligibility are being determined (e.g., for individuals establishing disability-based Categorical Eligibility)			

Notes:

¹⁹¹⁵⁽c) waiver enrollments are projected waiver participants during the approved five-year waiver period. FCSP enrollment sourced from the FCS Program Overview. MAC and TSOA enrollment estimate from MTP Quarterly Report (2023).

IV. Brain Injury Facilities, Services, and Provider Reimbursement

In this section, we review waivers, services, and facilities other states use to provide LTSS for individuals with brain injury. We compare these systems to the services and facilities available in Washington.

Waivers for People with Brain Injuries

First, we conducted a state-level review of 1915(c) HCBS waivers to identify services states have developed to address the long-term needs of people following a TBI.

We reviewed all 1915(c) waivers for adults with disabilities that were approved as of summer 2024—a total of 110 waivers in 42 states/District of Columbia. In each state, we identified the waivers for which a person with a long-term disability related to TBI would be eligible. We grouped states into categories with three levels of specificity to brain injury LTSS (Exhibit 10).

In our review, forty-two states/DC use fiftyone 1915(c) waivers to deliver HCBS to adults. We include multiple waivers for a single state when both waivers are used to provide services together or when multiple waivers identify persons with brain injury as an eligible group. For example, states such as Kentucky and Massachusetts have multiple brain injury waivers, while California and Washington have both a residential waiver (reimbursing facility-based round-the-clock services) and a complementary non-residential waiver (providing services at those facilities and in other settings).

We classify states/DC according to whether they have a "Brain injury waiver" (N=20), any "Brain injury eligible waiver" (N=11), or only "Other LTSS waivers" (N=11).⁸¹ Nine states do not use 1915(c) waivers to provide LTSS to adults.⁸² Thirty-two states reimburse waiver services exclusively on a fee-forservice (FFS) basis.⁸³ We compiled publicly posted FFS reimbursement rates for all waivers into a spreadsheet. This dataset includes 2024 published service-level reimbursement rates to providers (Appendix Data Sheet "1915c Waivers Service Rates").

⁸¹ Washington and California have a "brain injury eligible waiver" as well as an "other LTSS waiver." Since members may access both waivers, we classify both as "brain injury eligible" waiver states.

⁸² Arizona, New Jersey, Rhode Island, and Vermont do not use 1915(c) waivers. Delaware, Hawaii, New Mexico, Tennessee, and Texas have no adult HCBS 1915(c) waivers.

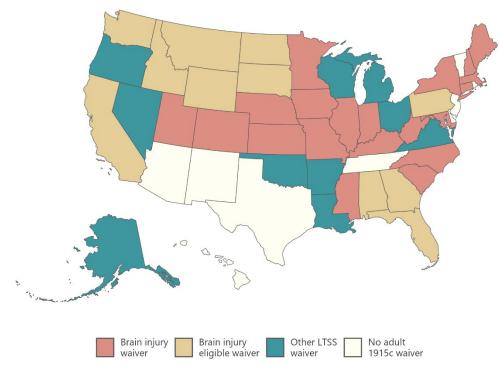
⁸³ Burns, A., Mohamed, M., & O'Malley Watts, M. (2023). *Payment rates for Medicaid home and community-based services: States' responses to workforce challenges*. Appendix Table 2. KFF.

Exhibit 10 Approach to Classifying Brain Injury and Other Waivers Ope Description Example The state has a waiver that requires The Illinois Brain Injury Waiver lime

Waiver type	Description	Example
(1) Brain injury waivers	The state has a waiver that requires beneficiaries to have a documented "traumatic" or "acquired" brain injury.	The Illinois Brain Injury Waiver limits waiver services to individuals with functional limitations resulting from an acquired brain injury (including TBI) as documented by a physician or neuropsychologist.
(2) Brain injury eligible waivers	The state does not have a brain injury waiver. The state has a waiver that references people with brain injuries as a target group.	The Idaho Aged & Disabled Waiver requires that providers of waiver day habilitation and supported employment services have training to work with individuals with traumatic brain injuries.
(3) Other LTSS waivers	The state has neither a brain injury waiver nor a waiver explicitly prioritizing people with brain injury. The state has an HCBS waiver for adults.	The Virginia Commonwealth Coordinated Plus Waiver provides HCBS to individuals who would be at risk for institutional placement if they did not have access to waiver services.

Exhibit 11

Map Classifying States by Brain Injury Waiver, Brain Injury Eligible, or Other LTSS Waiver



Notes:

Colors differentiate between states with a 1915(c) brain injury waiver (orange), a waiver that identifies persons with brain injury as a priority group in the CMS waiver application (tan), or only other LTSS waivers (green). States that do not use 1915(c) waivers primarily use 1115 demonstrations to provide HCBS.

Exhibit 11 shows which states are classified in the three brain injury categories described in Exhibit 10.

We classify Washington in the second category, "brain injury eligible waiver:" Apple Health does not have a brain injury waiver but provides services to individuals with brain injury through its Residential Services Waiver (RSW) and COPES Waivers.⁸⁴

Throughout this section, we will discuss three topics related to these waivers:

- 1) Differences between brain injury and other LTSS waivers.
- 2) Differences between brain injury waivers across states.
- 3) Types of "round-the-clock" services offered in facilities.

Comparing Brain Injury and Other Waivers. First, we compare the services offered in state brain injury waivers to waiver services in the other two categories.

We grouped waiver services using the federal HCBS taxonomy—a CMS-provided tool that enables researchers to categorize claims to make comparisons across states that use different procedure codes to describe similar services.⁸⁵

We calculated the percentage of states within each TBI category (brain injury waiver, brain injury eligible, other LTSS) that offer HCBS in each of the CMS categories (Exhibit 12). For example, 25% of states with brain injury waivers, 91% with brain injury eligible waivers, and 73% with other LTSS waivers offer nursing services.

We make four observations. First, many services are provided in all three types of waivers: three-quarters of all waivers offer "Home-Based Services" (e.g., chores, personal care), "Equipment, Technology, and Modifications" (emergency response system and home modifications), "Caregiver Support" (respite), "Day Services" (adult day care); "Case Management" (social service support); and "Round-the-Clock Services" in private residences and facilities.

Second, "Nursing" services are less common in brain injury waivers than waivers in the other two categories, which often target more general "aged and disabled" groups. This difference may reflect the distinct needs of waiver target populations: individuals with brain injuries may require more rehabilitative and behavioral support than ongoing skilled nursing services, which may be more commonly needed by senior enrollees or individuals with other chronic physical conditions.

Third, "Mental Health and Behavioral" and "Supported Employment" services were more common in brain injury than in other waivers. This pattern may reflect efforts to address the disproportionate impact of brain injuries on cognitive outcomes and the community-reintegration needs of working-age adults.

Fourth, the only category that we could not identify in Apple Health COPES and RSW waivers was "Financial Services."

⁸⁴ ALTSA Long-Term Care Manual. Chapter 7d: COPES.

⁸⁵ Peebles, V., & Bohl, A. (2014). The HCBS taxonomy: a new language for classifying home-and community-based

services. Medicare & Medicaid Research Review, 4(3), mmrr2014-004.

In this context, financial services almost always accompany programs that "support self-direction," such as permitting enrollees to purchase equipment or manage personal care providers. Twelve states use a 1915(c) waiver to deliver financial services (CO, GA, IA, KS, KY, LA, ME, MI, MN, MT, UT, and WI).

In some cases, such as Connecticut and New Hampshire, the department contracts with a "fiscal intermediary" but does not bill this work as a waiver service.

We reviewed "Mental Health and Behavioral" and "Supported Employment" services because they were more common in brain injury than in other waivers.

Mental Health and Behavioral Services.

Three-quarters of states with brain injury waivers offer *Mental Health and Behavioral* services. Four states offer substance use treatment services (CO, CT, NY, and SC); eleven states offer behavioral support, therapy, programming, interventions, or counseling (CO, CT, IN, IA, KA, KY, NH, NY, SC, UT, and IL); two states offer crisis interventions (NC and NH), peer mentorship (MA and CO), or neuropsychological evaluation (MO and IL), respectively.

In Washington, Apple Health offers tiered behavior support services to help clients remain in community settings. The highest level is provided in Enhanced Services Facilities (ESFs), where each resident receives a person-centered plan, including a crisis prevention protocol.

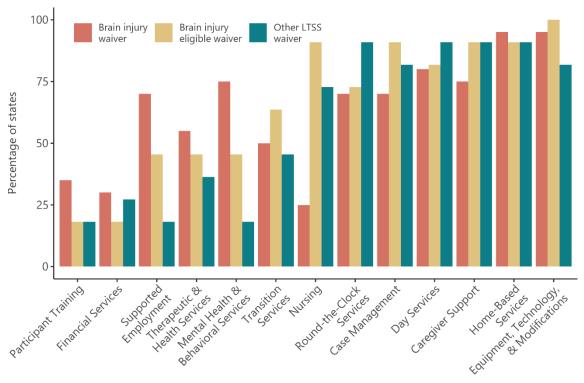


Exhibit 12

Percentage of States that Offer Service in HCBS Category by 1915(c) Waiver Category

Notes:

Forty-two states were categorized as having a "Brain injury waiver" (orange), "Brain injury eligible waiver" (tan), or "Other LTSS waiver" (green). The graph shows the percentage of waivers that provide a service in the HCBS category described on the x-axis.

In 2024, Apple Health added "Community Behavioral Health Support Services— Supported Supervision and Oversight" to its state plan using a Section 1915(i) option.

This service supports individuals with "mental illness and/or diagnosis related to traumatic brain injury" and aims to support participants' restoration of skills and "resiliency" necessary to live in communitybased settings.⁸⁶ One thousand two hundred Washington residents are projected to receive this new service while residing in adult group homes, assisted living facilities, and ESFs.

Supported Employment Services. Nearly three-quarters of states with brain injury waivers offer services to prepare or support participants to maintain employment. Six states offer "prevocational" services (CT, IA, IL, MN, MA, and ME), and 11 states offer "supported employment" services (CT, IA, IL, IN, KY, MA, MD, NC, NE, NH, and UT).

Supported employment programs commonly include informational interviews, job shadows, and financial literacy training. State programs place participants in business settings to increase interaction between clients with brain injuries and people without disabilities. lowa, for example, specifies that incentives cannot be paid to employers but allows for payments to compensate "coworker supports."⁸⁷

In Washington, ALTSA and the Division of Vocational Rehabilitation (DVR) offer supported employment services. The 2024-2027 DVR State Plan describes a plan to coordinate access with Apple Health for TBIaffected participants.⁸⁸

The 2017 Washington 1115 demonstration ("Medicaid Transformation Project") created the Foundational Community Supports (FCS) —Supported Employment service. While FCS can be "braided" with DVR, as a Medicaid program, FCS expedites access for people with qualifying behavioral or functional needs.⁸⁹

The FCS program reached a budgetary limit in 2024 and was forced to pause enrollment temporarily.⁹⁰

Comparing State Brain Injury Waivers.

Having reviewed the differences in the types of services offered by brain injury and other types of waivers, we now compare the characteristics of brain injury waivers in terms of budgetary restrictions, accessibility, and delivery of care.

⁸⁶ Centers for Medicare & Medicaid Services. (2024). WA-24-001. *1915(i) State plan amendment*.

⁸⁷ Iowa Department of Human Services. 2020. *Prevocational and Supported Employment Services*.

⁸⁸ Washington Department of Social and Health Services Division of Vocational Rehabilitation. (2025). *2024-2027 Amended state plan*.

⁸⁹ Washington State Health Care Authority. (2018). *Coordinating Division of Vocational Rehabilitation and FCS Services*.

⁹⁰ Washington State Health Care Authority. (2025). Foundational community supports frequently asked questions.

	5		y	Service plan		
State	Enrollment	Waitlist	Cost limit	review frequency	Self-directed services	Managed care
CO	1155	No	Institutional	12 months	Yes	No
CT	ABI I: 283	Yes	200% Institutional	12 months	Yes	No
СТ	ABI II: 327	Yes	150% Institutional	12 months	Yes	No
IL	3212	No	Institutional	12 months	Yes	Yes
IN	200	Yes	None	90 days	No	No
IA	1747	Yes	None	12 months	Yes	Yes
KA	723	Yes	None	12 months	Yes	Yes
	ABI: 383	Yes	None	12 months	Yes	No
KY	Long-term: 438	Yes	None	12 months	Yes	No
ME	250	Yes	Institutional	12 months	Yes	Yes
MD	175	No	Institutional	12 months	No	No
MA	Non-resid: 120	Yes	None	12 months	Yes	No
	Resid: 786	Yes	None	12 months	Yes	No
MN	1137	No	None	12 months	Yes	No
MS	1200	Yes	Institutional	3 months	Yes	No
MO	40	Yes	\$32,000	6 months	No	No
NE	230	No	None	12 months	No	No
NH	307	Yes	None	12 months	Yes	Limited
NY	5,132	No	None	12 months	No	No
NC	107	No	\$135,000	12 months	No	Yes
SC	1312	Yes	None	365 days	Yes	No
UT	142	Yes	None	12 months	Yes	No
WV	96	Yes	Institutional	6 months	Yes	No

Exhibit 13 Budget and Service-Delivery Characteristics of Brain Injury Waivers

Notes:

The table shows enrollment, existence of a waitlist, individual cost limit, service plan review frequency, whether the waiver provides opportunities for self-directed services, and whether the waiver mandates enrollment with an MCO. Enrollment figures are taken from Bates & Redmond (2024). Cost limit (appendix B), service plan review (appendix D), self-directed services (appendix E), and managed care (appendix I) are taken from waiver applications.

The existence of a waitlist is determined by statements in the application or online documentation. "Institutional" cost is conventionally the state nursing facility per diem reimbursement rate.

Exhibit 13 shows enrollment limits, waitlists, individual cost limits, frequency of service plan reviews, opportunities for participant self-direction of services, and use of managed care across brain injury waivers.

Enrollment Limits. States use enrollment caps to control the size and cost of brain injury waivers. Enrollment limits for brain injury waivers ranged from 40 (MO) to 5,132 (NY). This range reflects different levels of accessibility of waiver services between states. States with smaller budgets for waiver services are more likely to incorporate waitlists. Thirteen states have waitlists. Depending on the state, these waiting lists may take multiple years to process.⁹¹ Individuals who cannot access brain injury services may be able to access other waivers or receive short-term rehabilitation services through Medicaid State Plan programs.

Cost Limits. 1915(c) waivers must be costneutral for the *average* participant. As a result, states can spend more on some participants if waiver costs do not exceed net institutional costs for which they are intended to substitute.

Eleven states do not set an individual cost limit. Six states set the cost limit as the per diem institutional (usually, nursing facility) reimbursement rate in the state. Missouri sets a cost limit at \$32,000 per year, the only state with an HCBS limit less than the institutional equivalent. The Washington COPES and RSW waivers do not set limits. Service Plan Review Frequency. The service plan review is an assessment of the "appropriateness and adequacy" of provided services, often conducted by a case manager. Reviews may be used to increase or reduce access to services. By federal law, service plan reviews must be conducted at least annually. Four states (IN, MS, MO, and WV) require an assessment every three to six months. MCOs may require a review for specific services at a shorter interval than the "minimum schedule" specified in the waiver. The Washington COPES and RSW waivers conduct reviews annually.

Participant Self-Direction. Self-direction means that participants or their representatives have authority over managing some services.⁹² For example, participants may hire their own personal care providers or oversee a budget to purchase equipment. Self-direction is an alternative model to the standard "agency delivery model," in which a state or contracted private agency hires, trains, and supervises direct care workers.

Seventeen out of 24 brain injury waivers offer participants or caregivers some authority over managing their care. Often, a minority of participants will access this option.

For example, Minnesota offers its Brain Injury (BI) Waiver clients access to a "Consumer Directed Community Support" service (CDCS). Seven percent of Minnesota BI Waiver clients participate.

⁹¹ Bates, E., & Redmond, E. (2025). Home-and Community-Based Services: A comparison of brain injury waivers across the United States. *The Journal of Head Trauma Rehabilitation*, 40(3), 216-220.

⁹² Centers for Medicare & Medicaid Services (n.d.) *Selfdirected services*.

Clients can choose a personalized set of supports in areas of personal care, "treatment and training" (e.g., day services, extended therapy, counseling, supported employment), environmental modifications, and purchasing of goods and services.

A financial management service is a "mandatory and integral" component of participant self-direction. Minnesota emphasizes that CDCS provides more opportunities for the participant to "individually tailor and staff services" compared to standard self-direction models.⁹³

In Washington, COPES and RSW do not provide self-direction opportunities, but services accessed through the state plan (Community First Choice personal care) can be self-directed.⁹⁴

Managed Care Enrollment. Six waivers require that participants enroll with an MCO to receive at least some waiver services. This is a low proportion that reflects that brain injury remains a subgroup for whom Medicaid-managed care has not been fully integrated. In contrast, the Washington RSW and COPES waivers use an MCO to deliver behavioral health services.

Research into the potential impacts of managed care on brain injury rehabilitation is ongoing.

In a study of 318 California hospitals, members with TBIs enrolled with an MCO were discharged earlier from acute and post-acute care compared to enrollees in FFS Medicaid.⁹⁵

Interviews with waiver participants receiving Medicaid managed care services in Iowa suggested that MCOs are anecdotally more likely to delay provider payments and limit access to requested services. Respondents commented on the significant decline in the quality of case management by the contracted MCO, forcing clients to shoulder a larger responsibility for self-advocacy.⁹⁶

We reviewed 1115 demonstrations to investigate whether states are developing programs to facilitate the transition to managed care for members with complex, chronic conditions. Since 2024, North Carolina has used a 1115 Medicaid Demonstration to implement a program called "North Carolina Medicaid Tailored Plans."⁹⁷ Tailored Plans are a county-level managed care product designed to ensure continuity of support for Medicaid enrollees with complex needs during a transition to managed LTSS.

The state intends to use Tailored Plans to support 160,000 residents with "intensive behavioral health conditions." Individuals may transition from the standard managed care plan to a Tailored Plan if they have crises resulting in emergency department visits for psychiatric problems or use behavioral health crisis services.

⁹⁴ The New Freedom (NF) waiver offers enrollees in King and Pierce Counties the option to self-direct spending for personal care, health services, goods and equipment, home and vehicle modifications, and training. New Freedom provides a financial management support service.
⁹⁵ Yue, J., Krishnan, N., Toretsky, C., Hsia, R., Manley, G., Boscardin, W., . . . DiGiorgio, A. (2025). Insurance payer is

⁹³Minnesota Department of Human Services. (2022). Amendments to Minnesota's Bl, CAC, and CADI Waiver Plans.

associated with length of stay after traumatic brain injury. *American Journal of Managed Care*, 31(4). ⁹⁶ Arora, K., Rochford, H., Todd, K., & Kaskie, B. (2021). Medicaid managed care in Iowa: Experiences of older adults

and people with disabilities. *Disability and Health Journal*, *14*(1), 100975.

⁹⁷State of North Carolina. Department of Health and Human Services. (2023). *Medicaid Reform Section 1115 Demonstration Renewal Application*.

Eligibility criteria for a Tailored Plan include individuals currently receiving Medicaid TBI services, who are on the waiting list for services from the state 1915(c) TBI waiver, or whose "TBI otherwise is a knowable fact."⁹⁸

Facility-Based Round-the-Clock Services

Finally, after assessing differences between brain injury and other waivers and differences between brain injury waivers, we reviewed facility-based "round-the-clock" services delivered using waivers to investigate whether states use specialized facilities to deliver services.

Unlike behavioral and vocational services, "round-the-clock" support ensures the welfare of clients 24 hours a day, seven days a week. We identified these services in fourteen brain injury waivers, eight waivers that reference people with brain injury, and ten other LTSS waivers (Exhibit 14).

These services are delivered in private residences, communal residences (e.g., group homes, shared living, or adult foster care), and other non-institutional facilities (e.g., assisted living or residential care facilities).

Tiered Neurobehavioral Services. States often reimburse services within a setting at different tiers or levels of care. Tiers may explicitly refer to neurobehavioral needs. For example, Maine reimburses for three levels of group home services with incremental neurobehavioral care. Colorado reimburses for seven tiers of "Supported Living" delivered in a shared "Assisted Living Residence."⁹⁹

Montana's Level 2 "Behavior Management Assisted Living" is a service for residents who exhibit "adverse behaviors, such as verbal and physical aggression."¹⁰⁰ Level 3, "Specialized Assisted Living," targets individuals at the highest "risk of institutional placement," including people with TBI.

Maryland offers three levels of "residential habilitation" in group homes. The levels require different staffing ratios and duration of full-time supervision. People with brain injury may move between levels during "periods of behavioral or psychiatric instability."¹⁰¹

South Carolina offers services in "Community Transition Homes" and reimburses five levels of care. Tiers 3-5 are designated for individuals with behavioral health concerns requiring additional staffing. The highest level, "High Management," can be provided to up to three people who "display extremely challenging behaviors."¹⁰²

⁹⁸ North Carolina Medicaid Managed Care. (2024) Behavioral Health and Intellectual/Developmental Disability Tailored Plan Eligibility and Enrollment. *Appendix B – Tailored Plan eligibility criteria*.

⁹⁹ Code of Colorado Regulations. Health Facilities and Emergency Medical Services Division. 6 CCR 1011-1 Chapter 7 – Assisted Living Residences.

 ¹⁰⁰ Montana Department of Public Health and Human
 Services. (2021). *Big Sky Waiver, residential habilitation*.
 ¹⁰¹ State of Maryland (2025). *Application for a 1915(c) Home and Community-Based Waiver. Brain Injury Waiver*.
 ¹⁰² South Carolina Department of Disabilities and Special Needs (2023). *Head and spinal cord injury residential habilitation*.

Exhibit 14				
Waiver Residential and	Facility-Based	Services		

Waiver		Waiver Service (levels)		Per-diem reimbursement	
AK	Alaskans Living Independently	Residential Supported Living (Acuity Add-on)	Group Home or Assisted Living Facility	\$446.64	
CA	Assisted Living Waiver	Assisted Living Services (Level 5 for TBI)	Adult Residential Facility	\$275.25	
	Persons with Brain	Transitional Living Program	Assisted Living	\$762.07	
CO	Injury Waiver	Supported Living Program (6 Levels)	Residence	\$237.25 to \$453.04	
ID	Aged and Disabled Waiver	Daily Supported Living (2 levels)	Private residence	\$410.88 to \$756.48	
IN	Traumatic Brain Injury Waiver	Assisted Living (3 Levels)	Assisted Living Facility	\$101.98 to 132.04	
KY	ABI Long-Term Care Waiver	Supervised Residential Care (3 Levels)	Community Mental Health Center (Level 3)	\$300.00	
ME	Members with Brain Injury Waiver	Residential Habilitation (Neurobehavioral)	Group home setting (Provider-operated)	\$543.41 to \$645.87	
MD	Brain Injury Waiver	Residential Habilitation (3 levels)	Group home setting (Provider-operated)	\$274.64 to \$503.08	
MA	ABI Residential Habilitation Waiver	Residential Habilitation (12 levels)	Group home setting (Provider-operated)	\$211.95 to \$299.93	
		Customized Living	Assisted Living Facility	\$319.59	
MN	Brain Injury Waiver	Community Residential Services	Adult Corporate Foster Care Facility	\$422.65	
MS	Assisted Living Waiver	TBI Residential	Traumatic Brain Injury Residential Facility	\$486.22	
		, . Residential Habilitation (4	Group Home	40475 . 4000.00	
MT	Big Sky Waiver	levels)	Assisted Living Facility	124.75 to \$220.0	
OR	Aged & Physically	Residential Care Facility (4 levels)	Residential Care Facility	\$79.77 to \$126.37	
	Disabled Waiver	TBI Specific Contract	Adult Foster Home	\$287.03*	
SC	Head and Spinal	Residential	Group home setting	\$272.70 to	
UT	Cord Injury Waiver Acquired Brain Injury Waiver	(5 levels) Residential Habilitation Supports	(Provider-operated) Group home setting & private residences	\$525.00 \$592.29	
		Adult Family Home (5 levels)	Group home setting	\$137.60 to \$230.18	
WA	Residential Support Waiver	Assisted Living / Enhanced Adult Resid. Care (5 levels)	Assisted Living or EARC Facility	\$168.73 to \$208.62	
		Enhanced Services Facility (4 levels)	Enhanced Services Facility	\$390.95 to \$559.80	
WY	Comprehensive Waiver	Community Living Services (6 levels)	Group home setting (Provider-operated)	\$152.66 to \$495.18	

Residential Care Facilities. Across brain injury and other LTSS waivers, most states provide round-the-clock services in group homes and assisted living facilities. While these facilities are not federally regulated,¹⁰³ they exhibit similarities across states.

California and Oregon offer services in a third category of facility, "Residential Care Facilities," for clients with brain injury.

California Adult Residential Care Facilities (ARFs) and Residential Care Facilities for the Elderly (RCFEs) (ages 60+) provide longterm assisted living services to beneficiaries with brain injuries. The state regards these facilities as "social-based facilities," not "healthcare facilities,"¹⁰⁴ meaning that they are primarily responsible for supporting members' activities of daily living and functional needs (e.g., personal care) rather than providing medical care.

California modified its Assisted Living Waiver in 2024 to add a fifth tier of services to RCFE/ARFs. Participants who receive Tier 5 services require a nursing facility level of care and exhibit "severe mental/cognitive disabilities as a result of a TBI" that necessitate "intense, focused attention." RCFE/ARFs designated as TBI facilities are authorized to provide a "Residential Habilitation" service reimbursed at an addon rate of \$27.00 per hour.

¹⁰³ Pitz, L. (2020). The critical need for state regulation of assisted living facilities: Defining" critical incidents," implementing staff training, and requiring disclosure of facility data. *Minn. L. Rev.*, *105*, 1009

There are currently 78 ARFs in California, ranging in size from four to 185 beds. Nine ARFs classified as TBI facilities have six beds each.¹⁰⁵ There are 1025 RCFEs in California, of which 31 are classified as TBI facilities.

The Oregon Aged and Physically Disabled Waiver specifies three long-term care facilities: Adult Foster Homes, Assisted Living Facilities (ALFs), and Residential Care Facilities (RCFs). RCFs and ALFs house six or more residents, while Adult Foster Homes support five or fewer residents.¹⁰⁶

Residential Care Facilities support beneficiaries with greater care needs than ALFs and offer less independence.¹⁰⁷ Nursing facilities may be converted to RCFs, reflecting their institutional qualities. Oregon identifies persons with TBI as an "underserved" population for whom services are "significantly unavailable" and prioritizes licensing of RCFs that provide TBI services.

Transition Facilities. States differentiate between facilities according to whether they are designed to achieve "supported living" or "transitional living" goals. For example, while California ARFs are intended to be a long-term care option for individuals *leaving* transitional residential programs, the Mississippi TBI Residential Facility is a transitional residence: the facility "is not intended to be a lifelong option" but rather provides a "stepping-stone to independent community living."¹⁰⁸

¹⁰⁴ State of California Department of Health Care Services. (n.d.) *Residential Care Facilities provider enrollment*.

¹⁰⁵ State of California Department of Health Care Services. (2025). *Assisted Living Waiver (ALW) Program participating facilities*.

¹⁰⁶ Oregon Administrative Rules. (2025). *Chapter 309 Division 40 Adult Foster Homes*

¹⁰⁷ Oregon Administrative Rules. (2025). Chapter 411 Division54. *Residential Care and Assisted Living Facilities*.

¹⁰⁸ Mississippi Division of Medicaid. (2021). *Traumatic Brain Injury residential facility quality aAssurance standards*.

Georgia and Colorado explicitly offer and differentiate between both types of facilitybased services according to these goals.

The Georgia State Health Plan defines the requirements of a state "Residential Treatment and Rehabilitation Program" offered at Traumatic Brain Injury Facilities.

Georgia TBI facilities (six to 30 beds) can offer either "Transitional Living Program" or "Life Long Living Program" services.¹⁰⁹ Transitional services "prepare clients for "maximum independence," with a projected average residency of 300 days, while Life Long Living services are provided to clients whose recovery has plateaued and require "ongoing lifetime support."

The Colorado Brain Injury Waiver reimburses for "Transitional Living Program" (TLP) and "Supported Living Program" (SLP) services. These services are not duplicative: TLP services are intended to bridge postacute recovery to independence or longerterm residence in an SLP-approved facility. Clients receiving TLP services are assessed every six months, while clients receiving SLP services are assessed every six to 12 months.

State Plan Facilities. While facility-based round-the-clock services are a standardized category in the federal 1915(c) waiver system, specialized brain injury facilities may be financed using other mechanisms (e.g., classified as rehabilitative services under a Medicaid state plan).

In addition to Georgia, we identified state plan facilities in Michigan, North Carolina, and Iowa.

As a part of its state plan Brain Injury Services (BIS) program, Michigan offers up to six months of "Transitional Residential Services" in state-licensed adult foster care facilities with additional, specialized staffing requirements.¹¹⁰ Reimbursement rates are negotiated with BIS providers.

In North Carolina, "TBI Long Term Residential Rehabilitation" is a behavioral health service offered in "Supervised Living Facilities" (SLFs) with four beds or fewer.¹¹¹ Two tiers of supervision are specified; the second tier includes support for high-level behavior and medical needs. North Carolina reimburses for "High Risk Intervention – Level II Group Homes" as an Enhanced Mental Health Service at \$160.61 per day and for "High Risk Intervention – Level IV" at \$401.45 per day.

lowa offers "Community-based Neurobehavioral Rehabilitation" as a state-plan rehabilitation service in 3-5 bed facilities.¹¹² These services bridge post-acute and long-term care, with a treatment plan cap of 180 days. Medicaideligible residents must have a brain injury diagnosis and behavioral symptoms that have resulted in hospitalization, institutionalization, incarceration, or homelessness. Services are interdisciplinary, including behavioral, medical, and social support. Per diem reimbursement is negotiated with an MCO.

¹⁰⁹ Georgia Department of Community Health. Health Planning. (2025). Rule 111-2-2-34 Specific Review Considerations for Traumatic Brain Injury Facilities.

¹¹⁰ Michigan Department of Health and Human Services. (2025). *Medicaid provider manual.*

¹¹¹ North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services. (2022). State-funded TBI Long Term Residential Rehabilitation.

¹¹² lowa Administrative Code. (2016). 441.78.56(249^a) Communitybased neurobehavioral rehabilitation services.

To ensure that facilities meet quality standards, Michigan,¹¹³ Georgia,¹¹⁴ and Iowa¹¹⁵ require that state plan brain injury rehabilitation facilities be accredited by a third-party accrediting organization (the Commission on Accreditation of Rehabilitation Facilities).

Facility-Based Services in Washington. The Washington RSW waiver defines four facility classes within which four levels of behavioral services can be provided. Services in each facility class are reimbursed depending on the beneficiary's CARE and RSW level of care assessment.

Since 2016, the Enhanced Services Facility (ESF) has offered the highest level of care available through the waiver. Detailed characteristics and requirements of these facilities are specified in Washington law.¹¹⁶ ESFs cannot house more than 16 residents, must employ an on-site licensed nurse 24 hours per day, provide the state with a "person-centered" care plan for each admitted beneficiary, and employ an interdisciplinary staff capable of providing, at a minimum, mental health and chemical dependency services, medication management services, personal care, medical treatment, social services support, activities and diversion, dietary and nutrition services, and security. Mental health and behavioral services are delivered by an MCO through the client's private or Medicaid insurance. There are currently 14 licensed ESFs in Washington.¹¹⁷

As of November 2023, ESFs in Washington maintained 131 beds and supported 113 clients.¹¹⁸

Summary of Section IV

States use Medicaid waivers to develop LTSS for adults with disabilities. Extensive differences between states complicate the definition of a single industry standard. Out of 42 states that use waivers, 20 have waivers specifically for adults with brain injuries, 11 include adults with brain injury as an eligible group, and 11 do not reference brain injury. We identified reimbursement rates for services offered using these waivers (Appendix Exhibit A1). Brain injury waivers are more likely to include "Supported Employment" and "Mental Health & Behavioral Services" than other waivers, such as waivers for older adults and adults with physical disabilities. States with brain injury waivers organize their services differently, including setting budgetary restrictions and integrating person-centered (i.e., participant-directed services) methods to deliver care. Some states are gradually transitioning adults with TBI to managed care. Facility-based care is often limited to group home settings, with tiered reimbursement for neurobehavioral services. In some states, TBI facilities are time-limited to support the transition to independent living, while other states use facilities to provide lifelong residential support.

¹¹³ Michigan Department of Health and Human Services. (2025). *Medicaid provider manual.*

¹¹⁴ Georgia Department of Community Health. Health Planning. (2025).

¹¹⁵ Iowa Administrative Code (2022). 441.77.52(249^a)

Community-based neurobehavioral rehabilitation services. ¹¹⁶ For example, RCW 70.97 Enhanced Services Facilities and WAC 388-107 Licensing requirements for Enhanced Services Facilities

 ¹¹⁷ Washington State Department of Social and Health Services. Aging and Long-Term Services Administration. (n.d.) *List of Enhanced Services Facilities in Washington State*.
 ¹¹⁸ Washington Department of Social and Health Services.
 (2024). *Enhanced Services Facilities: Clients, facilities, and beds*.

V. Industry Standards

An "industry standard" includes *formal* requirements (e.g., law) as well as *informal* conventions (e.g., common practice). This report reviewed federal requirements of state Medicaid LTSS programs and investigated how states use the flexibility afforded by Medicaid waivers.

In this section, we summarize the regulatory standards we identified through this investigation, as well as practices advocated by non-governmental organizations that support people with brain injury.

Federal Standards

A Supreme Court decision (Olmstead v. L.C., 1999) following the passage of the Americans with Disabilities Act (1990) required that states must make noninstitutional services (i.e., Home Health) available to persons with disabilities if their needs can be accommodated in a community setting.

During the 2000s, this *legal standard* contributed to the development of an *informal standard*, often influenced by advocacy groups, that states should offer more extensive HCBS to victims of brain injury who would otherwise be at risk of institutionalization. In 2014, after a decade of stakeholder engagement, the federal government codified these standards, including requirements and goals, for providing LTSS in "community-based" settings.¹¹⁹

Increasing investment in HCBS reflects a normative goal that LTSS should improve the quality of life of people living with a chronic condition. The federal government has encouraged this standard by creating pathways for states to provide more community-based services, such as 1915(k) Community First Choice (CFC). Most states do not invest in these more generous services: as of 2022, Washington was one of only nine states that offered CFC as a Medicaid state plan service.

Otherwise, the federal government does not extensively regulate industry practices: states exhibit freedom ranging from LTSS eligibility criteria (e.g., the definition of an "institutional" level of care) and reimbursement systems to the features of facilities.¹²⁰

States have policy space to invest in services within local budget constraints. Therefore, our work investigated states' practices.

State Standards

Our investigation showed that different needs, goals, and budgetary capacities lead to implementating different Medicaid programs to provide LTSS to adults with TBI.

Typical State Services for Brain Injury

Some states have used Medicaid waivers to develop services for adults with brain injury. These waivers offer many of the same services provided to other groups with long-term needs but are more likely to include services that reflect the specific needs of working-age adults and individuals with cognitive impairments (e.g., supported employment and behavioral support services).

^{119 42} C.F.R. §§ 441.301(c)(4).

Facility-Based Services

We observed that the most common facility used to provide full-time support to adults with TBI is a group-home-style environment. States address participant neurobehavioral needs with tiered services but do not typically use specialized facilities. Washington's differentiation of Enhanced Services Facilities as a distinct facility tier is atypical.

Many states differentiate shorter-duration "transitional" living facilities from longerduration facility-based "supported" living programs. States often codify criteria for subsidizing the relocation of adults with behavioral support needs to institutional facilities out of state.

Accessibility and Self-Direction

Many Medicaid LTSS are restricted to individuals at risk of institutionalization and who voluntarily "spend down" their assets. States use other tools, such as enrollment caps, to ensure that costs do not exceed budget limits.

Across nearly all states, budgetary constraints result in a general scarcity of long-term services for Medicaid participants and their caregivers. This shifts responsibility for caregiving to informal providers.

Some states allow waiver participants with brain injuries to self-direct their services, including hiring personal care providers, purchasing equipment, and reimbursing informal caregivers. States often use 1115 demonstrations to develop these programs. While not explicitly targeted to individuals with brain injuries, Washington's "Medicaid Alternative Care" and "Tailored Supports for Older Adults" exemplify this approach.

Managed Care

"Managed" healthcare is overtaking fee-forservice as the industry standard for healthcare delivery in the U.S. States are implementing this transition deliberately and slowly for individuals with complex, chronic conditions. States have used 1115 demonstrations to stagger and support the integration of these groups.

Standards Advocated by Non-Governmental Organizations

The formal industry standards reflected in state rules governing brain injury services are often driven by values promoted by accreditation and advocacy groups.

Accreditation

Accrediting organizations are independent groups that certify that programs meet quality standards. Washington codifies the requirements of its brain injury facilities and services in state law; as an alternative to direct regulation, other states contract with an accrediting organization to set standards.

The Commission on Accreditation of Rehabilitation Facilities (CARF) is the only accrediting body with a brain injury program standard.¹²¹ Many CARF-accredited providers offer LTSS (such as group homes for adults with brain injury), but CARF does not use the term "LTSS" to describe these providers.

¹²¹ Berwick, D., Bowman, K., & Matney, C. (eds). *Traumatic brain injury: A roadmap for accelerating progress*. Washington, D.C. The National Academies Press.

The absence of this term highlights some ambiguity surrounding the distinction between post-acute, sub-acute, and LTSS in the brain injury service system. States most commonly require accreditation for providers and facilities described by CARF as "Medical Rehabilitation Programs."¹²² Within this domain, CARF accredits "Home and Community Services," "Residential Rehabilitation Programs," "Vocational Services," and "Brain Injury Specialty Programs."

Home and Community Services (HCS). HCS

programs are expected to employ an interdisciplinary staff (e.g., health, direct support, education, and coaching professionals) and deliver services in diverse settings (e.g., workplaces, private homes, residential facilities), which "optimize [...] the quality of life of the person served."

Residential Rehabilitation (RR) Program.

Residential programs may deliver services in either "transitional" or "long-term" residential settings. Services should target community integration and cultivate improved functional independence, social performance, and health outcomes. *Brain Injury Specialty Program.* HCS and RR sites can receive a "Brain Injury Specialty Program" (BISP) certification. A BISP delivers services that address the "unique medical, physical, cognitive, communication, psychosocial, behavioral, vocational, educational, accessibility, and leisure/recreational needs of persons with a brain injury. The criteria for an accredited BISP include efforts to:

- 1) Minimize environmental barriers to self-care and activities,
- 2) Maximize community inclusion,
- 3) Promote self-advocacy,
- 4) Recognize the strengths and needs of clients and their caregivers,
- 5) Support efforts to improve quality of life throughout the life span,
- Partner with community-based services to develop integrated recovery and inclusion services, and
- Advocate for increased access to brain injury services to regulators, legislators, and insurance companies.

¹²² CARF International. (2025). *Medical Rehabilitation Program descriptions*.

Advocacy Groups

The National Association of State Head Injury Administrators (NASHIA) and the Brain Injury Association of America (BIAA) are the two primary advocacy groups for people with brain injury in the U.S. In 2024, NASHIA and BIAA released a joint report on how states can support people with brain injury.¹²³ This report emphasized that state Medicaid administrators, legislators, and healthcare providers should recognize:

- The value of brain injury waivers to improve access to services;
- Opportunities to strengthen waivers by adding self-direction, employment, cognitive rehabilitation, peer support, and crisis-support services;
- Incorporating screening for brain injury in general LTSS waivers;
- Offering brain injury services through accessible state plan options; and
- 5) Prioritizing services for individuals involved in the criminal justice system, youth, and the unhoused.

Summary of Section V

Industry standards for the provision of LTSS to adults with TBI are structured by federal regulations, state-level budgetary constraints, and stakeholder engagement. The 2014 the Center for Medicare & Medicaid Services "HCBS final rule" codified normative goals of HCBS, including increasing community integration, privacy, and autonomy. To deliver services to adults with brain injuries, states comment that small, group home style facilities help achieve these objectives. Criteria for facility accreditation and statements by advocacy groups have contributed to these industry practices. States take steps to control costs, such as limiting enrollment in waivers, while increasing opportunities for participants with brain injury to self-direct services and reimburse informal care providers.

¹²³ National Association of State Head Injury Administrators and the Brain Injury Association of America. (2024). *CMS*

VI. TBI in Washington

In this section, we first describe the incidence of TBI-related hospitalizations in the state and the demographic characteristics of these adults. Second, using data from a smaller sample of medically insured adults in Washington, we describe select long-term healthcare outcomes for patients with TBI. Since the analyses in this section use administrative health care records, they necessarily omit and may not represent the population of adults with TBI who do not receive formal health care.

TBI Hospitalization in WA

Study Sample

We use administrative data from the Healthcare Cost and Utilization Project (HCUP) state inpatient database to describe adults, ages 18 and older, with a TBI discharge record from an inpatient hospital facility in Washington State between January 2016 and December 2022. Hospitalization discharge records contain information on patient demographic characteristics, such as age, sex, race, residential county, primary payer (i.e., health insurance), and diagnoses.

Adults with TBI were identified using the International Classification of Diseases. Tenth Revision, Clinical Modification (ICD-10-CM) codes proposed as a diagnostic definition of TBI by the Centers for Disease Control and Prevention (CDC).¹²⁴ Injury diagnosis codes distinguish an initial TBI encounter (an episode of care where a patient receives active treatment for a TBI), a subsequent TBI encounter (receipt of routine care during recovery), and a sequela TBI encounter (related to long-term symptoms after an initial TBI).¹²⁵ Between 2016 and 2022, 84% of inpatient hospitalizations related to TBI in Washington were for an initial encounter.

Exhibit 15 depicts the quarterly number of discharges following an initial TBI encounter for the three most common primary payer types: Medicaid (16%), Medicare (51%), and commercial insurance (25%).¹²⁶

On average, there were 1,399 initial TBI hospitalizations per quarter in Washington State between 2016 and 2022. Despite growth in the state population, the overall number of inpatient hospitalizations for TBI was stable for all three insurance groups between 2016 and 2021. Beginning in 2021, there was an increasing number of TBI hospitalizations for Medicare- and Medicaid-insured patients and a decline in the use of private/commercial insurance as a primary payer.¹²⁷

¹²⁴ Patients with a TBI were identified using the following ICD-10CM codes: S02.0, S02.1, S02.80, S02.81, S02.82, S02.91, S04.02, S04.03, S04.04, S06, S07.1. Hedegaard, H., Johnson, R.L., Warner, M., Chen, L.H., & Annest, J.L. (2016). Proposed framework for presenting injury data using the International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) diagnosis codes. *National Health Statistics Reports*, 89, 1-20.

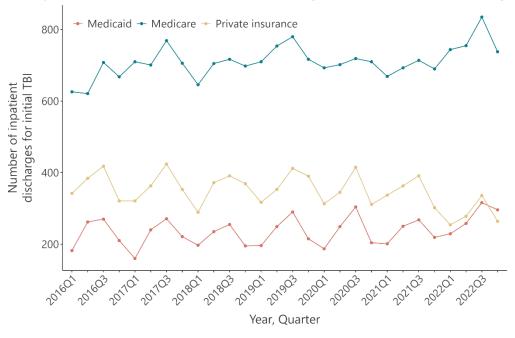
¹²⁵ Hedegard et al., (2016).

¹²⁶ The remaining 8% fall under other payment types such as self-pay and government programs (e.g., worker's compensation).

¹²⁷ Between 2019 and 2023, the proportion of adults ages19-64 with Medicaid coverage in Washington increased from14.7 to 16.2%.

Exhibit 15





Note: Data from the Healthcare Cost and Utilization Project state inpatient database (01/2016-12/2022).

We map the average annual incidence rate of adult TBI-related (initial encounter) hospitalizations between 2016 and 2022 in Exhibit 16.¹²⁸ Nine counties (Pierce, Walla Walla, Jefferson, Chelan, Cowlitz, Columbia, Clallam, Lewis, and Lincoln) had incidence rates above 90 hospitalizations per 100,000 per year; five counties (Garfield, Asotin, Klickitat, Whitman, Skamania, and Pacific) had rates below 60 hospitalizations per 100,000 per year. Annual average incidence rates were nearly identical (80 per 100,000 per year) across urban and rural settings.¹²⁹ This rate is comparable to nationally reported rates of TBI hospitalizations per 100,000 for rural and urban counties.¹³⁰

Patient Characteristics

Exhibit 17 summarizes the estimated annual incidence rate of TBI-related hospital discharges for demographic and payer groups between 2016 and 2022.

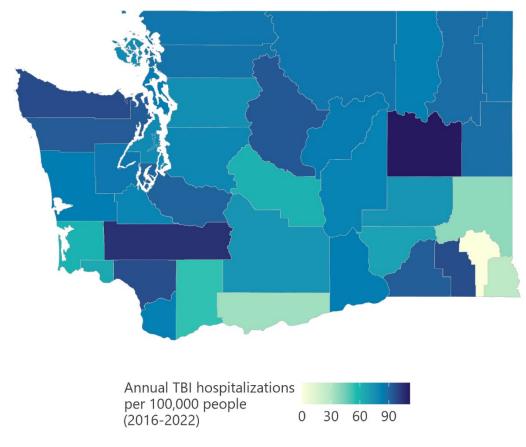
¹²⁸ Annual county-level adult population estimates come from the U.S. Census Bureau American Community Survey 5year samples.

¹²⁹ We classified counties as "metro" or "nonmetro" using USDA Rural-Urban continuum codes.

¹³⁰ Daugherty, J., Sarmiento, K., Waltzman, D., & Xu, L. (2022). Traumatic brain injury–related hospitalizations and deaths in urban and rural counties—2017. *Annals of emergency medicine*, *79*(3), 288-296.

Exhibit 16

Incidence Rate (per year, per 100,000 adults) of Initial TBI Encounter Discharges from Hospitals in Washington (2016-2022)



Note:

Data from the Healthcare Cost and Utilization Project state inpatient database (01/2016-12/2022).

Initial encounter Subsequent encounter Long-term consequence Number of Number of Number of Rate (per TBI Rate (per Rate (per TBI discharges **TBI discharges** 100,000 per 100,000 100,000 per discharges (% (% of TBI (% of TBI of TBI per year) year) year) discharges) discharges) discharges) (1) (2) (3) (4) (5) (6) **TBI** discharges 32,988 79.9 4,159 10.1 2,027 4.9 Female 12,686 (38.5%) 60.8 1,371 (33.0%) 6.6 650 (32.1%) 3.1 Male 20,297 (61.5%) 99.3 2,788 (67.0%) 13.6 1,377 (67.9%) 6.7 Age group: 18-24 1,857 (5.7%) 39.1 345 (8.3%) 7.3 81 (4.0%) 1.7 25-34 2,667 (8.1%) 34.7 408 (9.8%) 5.3 178 (8.8%) 2.3 323 (7.8%) 4.4 220 (10.9%) 3.0 35-44 2,438 (7.4%) 33.4 45-54 45.4 424 (10.2%) 6.5 229 (11.3%) 4.5 2,973 (9.0%) 55-64 4,599 (13.9%) 70.0 594 (14.3%) 9.0 477 (23.5%) 7.2 65-74 759 (18.2%) 15.0 383 (18.9%) 7.6 6,064 (18.4%) 119.3 396 (19.5%) 75+ 12,390 (37.6%) 370.9 1,306 (31.4%) 39.3 12.0 Race/ethnicity: Asian or PI 2,011 (6.1%) 49.5 217 (5.2%) 5.4 76 (3.7%) 1.9 Black 1,208 (3.7%) 72.3 124 (3.0%) 7.4 116 (5.7%) 6.9 2.5 Hispanic 45.2 486 (11.7%) 10.4 114 (5.6%) 2,080 (6.3%) Na. American 482 (1.5%) 64.8 61 (1.5%) 8.1 42 (2.1%) 5.6 Other 1,624 (4.9%) 342 (8.2%) 92 (4.5%) White 25,583 (77.6%) 81.1 2,929 (70.4%) 9.3 1,587 (78.3%) 5.0 Payer type: Medicaid 5,344 (16.2%) 92.0 823 (19.8%) 14.2 462 (22.8%) 7.9 12.0 Medicare 16,882 (51.1%) 186.2 1,930 (46.4%) 21.4 1,086 (53.6%)

Exhibit 17

Characteristics of Patients Hospitalized with a TBI in Washington (2016-2022)

Notes:

Private

Other

Data from the Healthcare Cost and Utilization Project state inpatient database (01/2016-12/2022). Denominator data for age groups, sex, and race/ethnicity is from the Washington State Office of Financial Management Forecasting division population and demographics files. Denominators for payer groups are estimated from the product of annual, age-stratified population estimates from OFM and estimates of the proportion of adults by health insurance type in Washington from the 1-year 2019 American Community Survey.

1,136 (27.3%)

270 (6.5%)

3.7

"Other" race is combined with missing (no response).

8,228 (24.9%)

2,534 (7.7%)

Rates are missing where estimated population counts were unavailable, and the population rate could not be calculated. Rate (per 100,000) is the average annual incidence rate over the seven-year data period (2016-2022).

27.1

The first two columns describe outcomes for adults with an initial TBI encounter, the next two describe adults hospitalized for a subsequent TBI encounter, and the last two describe adults hospitalized for long-term complications (i.e., sequela of TBI).

Over the study period, there were 32,988 initial TBI discharges (80 per 100,000 adults per year), 4,159 subsequent TBI discharges (10 per 100,000 adults per year), and 2,027 hospitalizations with a long-term TBI complication (4.9 per 100,000 adults per year). Across all three encounter types, more than 50% of patients were male, white, and/or Medicare insured.

364 (18.0%)

115 (5.7%)

1.2

Across age groups, the highest proportion of discharges was those aged 75 and older (over 30% for initial and subsequent TBI encounters).

Adults in these TBI groups were hospitalized for different durations. Hospital stays for initial visits ranged from one day to 334 days, with a median of four days. Stays for subsequent visits ranged from one to 364 days, with a median of ten days. Stays for long-term complications ranged from one to 256 days, with a median of five days.

Health Care Utilization and Outcomes

The HCUP state inpatient database is comprehensive (including every hospital discharge in the state) but does not permit analysis of healthcare utilization in nonhospital settings. Furthermore, it does not allow us to track an individual's healthcare use over time. To examine other healthcare outcomes for individuals with TBI, we accessed data from the Washington State All Payer Claims Database (WA-APCD).¹³¹ This database includes insurance claims for healthcare use in both inpatient and outpatient settings.

The WA-APCD only includes information for a subset of adults with insurance. It does not include data for uninsured individuals, individuals with self-funded employer insurance, federally insured individuals (e.g., TRICARE and VA health care), and individuals covered by Indian Health Services. WA-APCD estimates that approximately 70% of the Washington population is represented in the database during fiscal year 2023.¹³² Further, our sample *only* includes Medicare Advantage (MA) members, not those who are enrolled in Medicare Fee-For-Service (FFS). Medicare FFS is the original Medicare program offered directly through the federal government, and MA is offered by private insurers. In 2024, about 53% of Medicare beneficiaries in WA were enrolled in MA plans.¹³³

Sample and Study Design

Our sample comprises WA-APCD members, ages 18 and older, who were diagnosed with a TBI between January 2016 and December 2019.¹³⁴ Information related to the characteristics of patients in this sample can be found in Exhibits A1 and A2 of Appendix II.

For these analyses, we identify, for each patient, the first TBI encounter witnessed in the sample period (i.e., the *index* TBI).¹³⁵ There are 71,248 index TBI encounters in our sample. We examine measures of health care use occurring within intervals of one year and two years following the first TBI encounter. We measure emergency department (ED) visits and hospitalizations across these intervals.

¹³¹ Washington State Health Care Authority

⁽HCA) (2024). Washington State All Payer Claims Database (WA-APCD). Deidentified claims data from the WA-APCD were accessed under a data use agreement. ¹³² Washington State All-Payers Claims Database and Lead

Organization biennial report (2024).

¹³³ Freed, M., Fuglesten, B., Damico, A., Neuman, T. (2024, August 8) *Medicare Advantage in 2024: Enrollment updates and key trends*. KFF.

 ¹³⁴ To avoid potential discontinuities in care related to COVID-19, we end our analysis sample in December 2019.
 ¹³⁵ These are initial TBIs identified using the same ICD-10-CM codes as before.

Exhibit 18 describes the characteristics of adults at the time of index TBI treatment. We group these adults by the location of treatment. Adults who had an inpatient hospitalization are classified in "hospitalization"; adults without an inpatient hospitalization but with an ED visit are classified in "emergency department"; all other adults whose index TBI involved neither hospitalization nor an ED visit are classified in "outpatient."¹³⁶

Exhibit 18

Characteristics of Patients at the Time of Index TBI Encounter, Washington (2016-2019)

	Hospitalization	Emergency department (ED)	Outpatient
Patient characteristics			
Female	0.40	0.50	0.59
Age group:			
18-24	0.07	0.16	0.19
25-34	0.12	0.23	0.20
35-44	0.09	0.15	0.16
45-54	0.12	0.14	0.15
55-64	0.16	0.14	0.15
64-74	0.16	0.09	0.09
75+	0.28	0.09	0.05
Primary payer:			
Medicaid	0.52	0.55	0.35
Medicare	0.31	0.13	0.11
Commercial	0.18	0.32	0.54
Diagnosis characteristics			
TBI is the primary diagnosis	0.84	0.84	0.63
Severity level:			
Mild	0.03	0.38	0.68
Moderate	0.03	0.20	0.12
Serious	0.13	0.25	0.14
Severe	0.27	0.08	0.03
Critical	0.54	0.09	0.04
Observations	8,041	41,909	17,358

Notes:

Data come from the WA-APCD (2016-2019).

TBI severity levels correspond to Abbreviated Injury Scores (AIS); this is different from the severity level assignment described in Exhibit 2.

"outpatient" by the APCD (e.g., rural and mental health clinics), and the place of setting code that corresponds to "office visit."

¹³⁶ In our analysis, ED care is determined by an ED-specific charge flag provided in the data, and outpatient care is determined by both place of setting codes designated as

In our APCD sample of adults with a TBI, 8,041 (12%) adults are hospitalized, 41,909 (62%) adults receive ED care without a hospitalization, and 17,358 (26%) adults receive outpatient care but did not visit the hospital or ED.¹³⁷

As summarized in Exhibit 18, adults diagnosed with a TBI as a part of a hospitalization are more likely to be male and older in age. Hospitalized patients are also more likely to be diagnosed with a critical-level TBI (54%).¹³⁸ We observe the opposite for TBI patients treated in an outpatient setting who are predominantly female, younger in age, and/or diagnosed with a mild TBI. The proportion of patients for whom TBI is the primary reason for the health care encounter is smallest among outpatient visits relative to other treatment settings—63% versus 84%. Medicaid-insured adults account for approximately half of hospitalizations and ED care encounters, whereas commercially insured adults account for most outpatient care encounters.

Health Care Utilization

Exhibit 19 summarizes health care utilization over the first two years after an index TBI encounter. Outcomes include any ED visits or hospitalization. For example, the first column of Exhibit 19 indicates that 45% of TBI patients who were hospitalized experienced an ED visit within one year of the index event, and 50% experienced an ED visit within two years.

We do not see large differences in longterm care utilization outcomes within one year versus two years. This would suggest that a significant proportion of individuals who experience these outcomes do so within the first year after the index TBI.

Exhibit 19

	Hospitalization	Emergency department (ED)	Outpatient
ED visit:			
Occurrence within one year	0.45	0.46	0.27
Occurrence within two years	0.50	0.52	0.34
Hospitalization:			
Occurrence within one year	0.19	0.10	0.05
Occurrence within two years	0.23	0.14	0.07
Observations	8,041	41,909	17,358

Long-Term Health Care Utilization Following Index TBI, Washington (2016-2019)

<u>Note</u>:

Date comes from WA-APCD 2016-2019.

¹³⁷ It is not uncommon that adults who were hospitalized or visited the ED during their index TBI to also have insurance claims for care in other, less intensive settings.

¹³⁸ We used the cat_trauma function from the icdpicr R package ("ICD Programs for Injury Categorization in R") to assign Abbreviated Injury Scores (AIS) to ICD-10-CM TBI diagnoses.

Approximately 45% of TBI patients who received ED care or were hospitalized had an ED visit within a year. For reference, in a study from California (2005-2014), 41% of adults had an ED visit or hospital readmission in the first year after their hospital or ED index TBI diagnosis.¹³⁹ In Washington, TBI patients who were hospitalized in response to their index TBI were twice as likely to be re-hospitalized within a year as patients who received ED care (20% vs. 10%), and four times as likely as patients who received outpatient care (20% vs. 5%).

The findings summarized in Exhibits 18 and 19 lend corroborating evidence that the most severe TBIs are associated with hospitalization and greater long-term healthcare use. Importantly, we cannot determine if greater long-term healthcare use is *caused* by the TBI or if those who have greater health care needs are also more likely to sustain a TBI.

Outcomes Following Hospitalization

The care pathway experienced by TBI patients who start with hospital-based treatment can vary widely; some return to the home environment, while others are transferred to a post-acute rehabilitation facility or a sub-acute care setting such as a nursing home (see Exhibit 4).

Where a patient goes after being discharged from a hospital can depend on several factors, including the severity of a TBI, age, insurance coverage, and long-term care needs.¹⁴⁰ Evidence suggests that the receipt of appropriate care after discharge from a hospital facility is associated with longer-term functional improvements and independence.¹⁴¹

Given the relevance of post- and sub-acute care to long-term outcomes after hospitalization, in this section, we first describe discharge destinations for individuals who are hospitalized during their index TBI. Second, we examine the use of the ED and rehospitalization within the first year period.

We look at healthcare use across groups with similar levels of TBI severity but different discharge destinations. We describe outcomes separately by age group.

Discharge Destination. In Exhibit 20, we describe the prevalence of the four most common destinations (in our sample) where patients go after being discharged from a hospital facility. These include:

- Discharge to self-care at home (routine discharge),
- 2) Discharge/transfer to a skilled nursing facility (SNF),
- 3) Discharge home with professional services (e.g., Home Health), and
- 4) Discharge/transfer to an inpatient rehabilitation facility (IRF).¹⁴²

¹³⁹ Hsia, R., Markowitz, A., Lin, F., Guo, J., Madhok, D., & Manley, G. (2018). Ten-year trends in traumatic brain injury: a retrospective cohort study of California emergency department and hospital revisits and readmissions. *BMJ Open*, *8*(12), e022297.

¹⁴¹ Rosenbaum, A.M., Gordon, W.A., Joannou, A., & Berman, B.A. (2018). Functional outcomes following post-acute rehabilitation for moderate-to-severe traumatic brain injury. *Brain Injury*, *32*(7), 907-914.

¹⁴² Following Yue et al. (2025), we use the following patient discharge status codes to define the four discharge

¹⁴⁰ Berwick, D., Bowman, K., & Matney, C. (eds). (2022).

In our sample, 93% of adults hospitalized with a TBI were discharged to one of these settings.

The proportion of adults who are discharged to a SNF or home with professional services largely increases after the age of 65 (Exhibit 20). These services are automatically covered after a qualifying inpatient stay (>3 days) for Medicare enrollees.¹⁴³ We observe corresponding decreases in the proportion of adults discharged home to self-care among the Medicare eligible aged population.

Patients under the age of 65 are relatively more likely to be discharged to a rehabilitation facility (about 10%). More than 75% of adults under the age of 65 are discharged to self-care at home after their hospitalization for TBI.

Subsequent Healthcare. We next describe healthcare outcomes within one year of the index TBI hospitalization based on discharge destination.¹⁴⁴ Since most adults ages 65 and older in Washington have Medicare coverage (95%),¹⁴⁵ Panels A and B of Exhibit 21 separately show outcomes for patients with a *severe/critical* TBI who are under the age of 65 (panel A) and ages 65 and older (panel B), respectively.¹⁴⁶ Adults under 65 who were discharged to self-care had the lowest rates of subsequent re-hospitalizations but a similar number of ED visits over the first year relative to other discharge destinations.

Individuals who were discharged to a SNF, indicating a continued need for medical oversight (see Exhibit 4), had re-hospitalization rates more than double that of individuals who were discharged to their home, with or without professional services.

Adults 65 and older, who were discharged to self-care also had the lowest rates of rehospitalization within the first year relative to other discharge destinations. Individuals who were discharged to a SNF, home with professional services, or a rehabilitation facility had similar re-hospitalization rates.

Overall, we observe moderate differences in healthcare use outcomes across different discharge destinations for both the younger and older age groups. Note, in these analyses, we estimate the *correlation* between discharge destination and outcomes. We cannot establish if differences in healthcare outcomes are *caused* by discharge to different post-acute care locations.

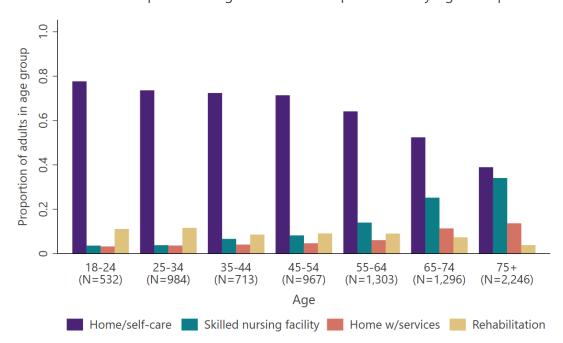
categories: home (1, 7), SNF (3, 64, 83, 92), home with services (6, 81, 86), and IRF (62, 90).

Yue, J., Krishnan, N., Toretsky, C., Hsia, R., Manley, G.,
 Boscardin, W., ... & DiGiorgio, A. (2025). Insurance payer is
 associated with length of stay after traumatic brain
 injury. *The American Journ of Managed Care*, *31*(4), 173-181.
 ¹⁴³ Center for Medicare & Medicaid Services. (n.d.) Skilled
 Nursing Facility Care.

¹⁴⁴ In Exhibits A3, A4, and A5 of Appendix II, we include tables that additionally stratify discharge destination and health care outcomes by payer type and describe outcomes experienced within two years of the index TBI hospitalization. ¹⁴⁵United States Census Bureau (2024). Health Insurance Coverage by and Type by State.

¹⁴⁶ 80% of patients were that were hospitalized were diagnosed with a severe or critical TBI.

Exhibit 20 Destination Upon Discharge from a TBI Hospitalization by Age Group

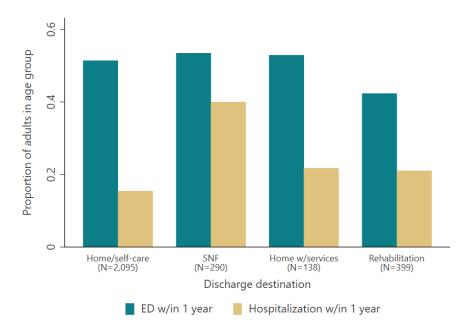


Notes:

Data come from WA-APCD (2016-2019).

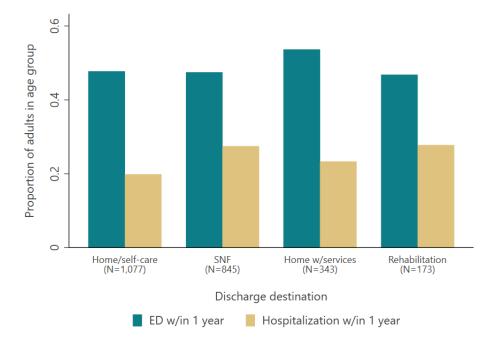
Each bar represents the proportion of adults in each age group that discharge to each destination.

Exhibit 21 Health Care Outcomes Within One Year of Severe/Critical TBI Hospitalization



a) Adults Under 65





Notes:

Data from WA-APCD (2016-2019 Each bar represents the proportion of adults in each discharge destination that experience each outcome.).

II. Conclusion

TBI is commonly referred to as an "invisible" disease: many serious TBIs do not include outward signs of injury, and *systemic* complications of brain injury can evolve slowly over time, making their connection with an original injury difficult to establish.

While many diseases can be addressed using medical interventions, the needs of brain injury survivors are often functional, behavioral, and social. A TBI may occur at any age and, therefore, impacts relationships and productive activity across the lifespan. These burdens increase the importance of LTSS in addressing barriers to community, family, and workplace reintegration.

State Methods and Industry Standards.

In the absence of accessible, lifelong, private long-term care coverage, Medicaid serves as an LTSS safety net in the U.S. The Americans with Disabilities Act and related case law require that states offer LTSS in a community-based setting if medically feasible, but states administer their own Medicaid programs, including choosing services and eligibility criteria.

Industry standards for providing LTSS to adults with TBI are influenced by these regulations, state budgetary constraints, and stakeholder engagement.

While states have similar normative goals such as supporting recovery of functional independence, compensating and supporting informal caregivers, or ensuring that facility-based services are accessible in community-based environments—different budgetary capacities contribute to variation in the accessibility of these services among Medicaid-insured adults between states.

Our research of Medicaid waivers and demonstrations provides corroborating evidence that brain injury programs offer common LTSS typical of programs that support adults with other physical disabilities, as well as services to address specific behavioral and social needs experienced by adults with brain injuries.

Services more commonly observed in brain injury programs include employment and behavioral support. Supported employment may include assistance finding paid employment or placement in a setting with other adults with disabilities. Behavioral and mental health supports are similarly diverse, ranging from programs to help adults cope with new adversities and develop resilience to crisis interventions necessary to stabilize an individual at risk of institutionalization.

Beyond specific services, states carefully incorporate methods such as managed care and self-direction into brain injury LTSS programs. These state-level initiatives reflect efforts to build sustainable and coordinated interventions while promoting self-advocacy and independence.

States can choose different statutory pathways to implement these interventions. While we observed that Washington's ALTSA delivers services in nearly all categories, the state does not have a dedicated Medicaid program to provide brain injury services. The Aging and Long-Term Support Administration is developing programs to support informal caregivers. Still, many existing state initiatives are often only accessible to older adults (e.g., adults 55 years and older), in some parts of the state (e.g., self-directed waiver services in Pierce and King Counties), or to individuals with significant behavioral challenges (e.g., facility-based RSW services).

Stakeholders in Washington representing individuals who have sustained TBIs reported that increasing the accessibility of services could have more impact than developing new services.¹⁴⁷

Limitations of the Industry and State Review.

Our conclusion—that the boundaries of brain injury services in many states are not well-defined—is also a limitation of our research. For example, we do not systematically document all relevant Medicaid authorities or examine how private insurance, military benefits, and other statefunded programs interact with Medicaid services. Additionally, our review did not comprehensively document services outside the conventional scope of Medicaid LTSS, such as programs that do not require an institutional level of care or post-acute facilities (e.g., short-term rehabilitation) that are not reimbursed through HCBS waivers.

Traumatic Brain Injury in Washington

Our analysis of the incidence of TBI in Washington described the demographics of this population as well as differences in the setting of diagnosis, discharge, and healthcare outcomes across groups. The incidence of TBI-related hospitalization in Washington impacts all ages: the risk of a TBIrelated hospitalization among adults older than 75 years is ten times greater than that of individuals ages 18-54, but approximately onethird of hospitalizations are for those younger adults (ages 18-54). Men have a 1.6 times higher rate of initial hospitalization for a TBI relative to women and more than twice the rate of hospitalizations for subsequent encounters and long-term issues related to a brain injury. While older, Medicare-insured adults are most vulnerable, Medicaid-insured adults are hospitalized with a TBI at over three times the rate of privately insured adults.

We estimate that nearly three-quarters of adults under 65 years who are hospitalized with a brain injury in Washington are discharged to self-care. Those who are discharged to an SNF or a rehabilitation facility, indicating a continued need for medical oversight, are more likely to be re-hospitalized within a year of the initial TBI.

Limitations of the Analysis of TBI in Washington.

Our investigation into the incidence and demographics of brain injury in Washington is strengthened by our integration of two data sources covering different populations and locations of care. However, each analysis has limitations. Neither administrative data set can measure health outcomes among adults who did not receive professional care. Furthermore, our analysis of insurance claims excludes a large proportion of this population, including the uninsured, self-funded employer-insured, and federally insured individuals (e.g., TRICARE and VA health care).

This work reflects the potential value of additional investigation into the relationship between risk of TBI, access to appropriate care, and long-term healthcare utilization in Washington.

¹⁴⁷ LTSS Trust Commission Feedback Sessions Summary (2020).

Appendices

Traumatic Brain Injury and Long-Term Services and Supports in Washington State

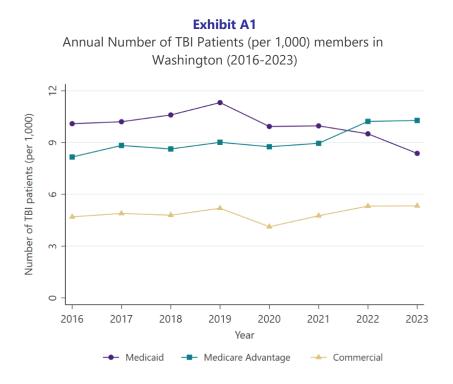
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I. Data

We have posted the Excel sheet "1915c Waivers Services Rates" which provides FFS reimbursement rates from state 1915c waivers for adults with disabilities.¹⁴⁸ Each tab of the sheet shows waiver rates published online in the summer of 2024 for each state waiver incorporated in our review. Sheets identify the state, agency name, waiver names, and data source.

¹⁴⁸ https://docs.google.com/spreadsheets/d/1b9N5rU0wcTjueNq7Tc7h8xPpVqgEH1CQRP54LPUCzCk/edit?usp=sharing.

II. TBI in Washington: Tables and Figures



Notes

The figure summarizes the number of individuals who are diagnosed with any TBI (per 1,000 APCD members per year) by insurer type. Data come from the WA-APCD (2016-2023).

Calculated as the rate (per 1,000) of total WA-APCD members in each payer type (member counts provided by WA-APCD).

Exhibit A2

Annual Number of TBI Patients (per 1,000) Members in Washington (2016-2023)

	Average number of TBI patients (% of TBI patients)	Rate (per 1,000 APCD members per year)
Members with a TBI	25,631	7.23
Female	12,927 (50%)	5.37
Male	12,710 (50%)	5.98
Age group:		
18-24	3,470 (14%)	6.97
25-34	4,880 (19%)	6.48
35-44	3,832 (15%)	6.04
45-54	3,729 (15%)	6.43
55-64	4,143 (16%)	6.03
65-74	2,989 (12%)	3.73
75+	2,846 (11%)	5.65
Payer type:		
Medicaid	11,968 (47%)	10.00
Medicare Advantage	4,714 (18%)	9.11
Commercial	8,948 (35%)	4.89

Notes:

The table describes the prevalence of demographic characteristics of individuals diagnosed with any TBI over 2016-2023.

Calculated as the rate (per 1,000) of total WA-APCD members in each payer type (member counts provided by WA-APCD).

Data come from the WA-APCD (2016-2023).

index TBI Patient Discharge Destination from Hospital Facility by Age Group—wA-APCD (2016-2019)							
	18-24	25-34	35-44	45-54	55-64	65-74	75+
Medicaid:	0.79	0.85	0.80	0.75	0.64	0.26	0.19
Home/self-care	0.76	0.72	0.71	0.68	0.62	0.38	0.29
Skilled nursing facility	0.03	0.04	0.06	0.09	0.15	0.31	0.38
Home w/services	0.04	0.03	0.03	0.05	0.06	0.11	0.12
rehabilitation facility	0.10	0.12	0.08	0.09	0.08	0.07	
Medicare Advantage:					0.11	0.60	0.68
Home/self-care					0.53	0.56	0.41
Skilled nursing					0.23	0.24	0.33
facility Home w/services Inpatient					0.09	0.12	0.14
rehabilitation facility						0.07	0.04
Commercial:	0.21	0.15	0.18	0.21	0.26	0.15	0.13
Home/self-care	0.84	0.82	0.80	0.82	0.75	0.64	0.45
Skilled nursing facility					0.08	0.22	0.33
Home w/services					0.05	0.10	0.14
Inpatient rehabilitation facility	0.15	0.12	0.12	0.10	0.12	0.11	0.05
Observations	532	984	713	967	1,303	1,296	2,246

Exhibit A3 Index TBI Patient Discharge Destination from Hospital Facility by Age Group—WA-APCD (2016-2019)

Notes:

This table describes the probability of discharge to a given destination following hospitalization with an index TBI; prevalence is summarized by age group and payer type.

Each column tabulates the proportion of hospitalized adults in each age group who are discharged to each destination (by payer type). Data come from the WA-APCD (2016-2023).

-- Cells are suppressed if the number of observations is less than 11.

Exhibit A4

	5			
	Home/self- care	Skilled nursing facility	Home w/services	Inpatient rehabilitation facility
Medicaid				
Emergency department visit:				
Within one year	0.56	0.55	0.59	0.45
Within two years	0.61	0.60	0.62	0.50
Hospitalization:				
Within one year	0.17	0.39	0.30	0.21
Within two years	0.18	0.41	0.35	0.24
Observations	2,171	265	139	308
Commercial				
Emergency department visit:				
Within one year	0.25	0.38	0.31	0.31
Within two years	0.31	0.45	0.39	0.37
Hospitalization:				
Within one year	0.11	0.34		0.22
Within two years	0.13	0.36		0.23
Observations	671	47	36	107

Health Care Use Outcomes by Discharge Destination from Hospital Facility, Individuals with Severe/Critical TBI Age 64 and Under

Notes:

This table describes the probability of healthcare outcomes (ED visit or hospitalization) within one year or two years of discharge from a hospital facility for individuals under 65 who are treated for a severe/critical index TBI; probabilities are summarized by discharge destination and insurance type.

Each column tabulates the proportion of hospitalized adults who experience each outcome by discharge destination (by payer type).

Data come from the WA-APCD (2016-2023)

-- Cells are suppressed if the number of observations is less than 11.

Exhibit A5

Health Care Use Outcomes by Discharge Destination from Hospital Facility, Individuals with Severe/Critical TBI Ages 65 and Older

	Home/self-care	Skilled nursing facility	Home w/services	Inpatient rehabilitation facility		
Medicaid						
Emergency department visit:						
Within one year	0.53	0.53	0.45	0.47		
Within two years	0.61	0.58	0.53	0.57		
Hospitalization:						
Within one year	0.08	0.10				
Within two years	0.13	0.14				
Observations	233	241	75	30		
Medicare Advantage						
Emergency department visit:						
Within one year	0.444	0.46	0.55	0.49		
Within two years	0.50	0.53	0.60	0.53		
Hospitalization:						
Within one year	0.27	0.40	0.32	0.40		
Within two years	0.33	0.45	0.37	0.44		
Observations	990	641	280	115		
Commercial						
Emergency department visit:						
Within one year	0.49	0.52	0.51	0.44		
Within two years	0.57	0.58	0.55	0.53		
Hospitalization:						
Within one year	0.05					
Within two years	0.06					
Observations	229	130	55	34		

Notes:

This table describes the probability of healthcare outcomes (ED visit or hospitalization) within one year or two years of discharge from a hospital facility for individuals ages 65 and older who are treated for a severe/critical index TBI; probabilities are summarized by discharge destination and payer type.

Each column tabulates the proportion of hospitalized adults who experience each outcome by discharge destination (by payer type).

Data come from the WA-APCD (2016-2023)

-- Cells are suppressed if the number of observations is less than 11.

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