

Senate Memorial 30: Exploring the Feasibility of Comprehensive Coverage of Brain Injury Care and a Brain Injury Registry for New Mexico

The Senate Memorial 30 Working Group for the Governor's Commission on Disability

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Executive Summary

The purpose of the present report is to explore the feasibility of providing comprehensive coverage for brain injury (BI) services and of establishing a brain injury registry for the citizens of the state of New Mexico.

Brain injury is a serious public health problem in New Mexico, with between 21,000 and 32,000 New Mexicans estimated to be disabled by a traumatic brain injury (TBI). Persons living with BI commonly have life-long impairments in motor control, sensory function, emotional regulation, and cognitive control. For these patients, worse functional outcomes can result from not having life-long access to evidence-based treatment for BI due to lack of coverage. The system of care for BI in NM is also fragmented, resulting in difficulty accessing resources, and some patients must leave the state to obtain necessary rehabilitation treatment. There is a need not only for funding for comprehensive coverage for BI care, but also for interventions to support and integrate the system of care itself.

Coverage for BI care in New Mexico is currently provided by four types of products: Medicare plans; commercial insurance plans; Medicaid insurance plans; and the Brain Injury Service Fund (BISF) for non-Medicaid patients. All of these have certain gaps and shortcomings associated with their coverage. For instance, Medicare does not pay for post-acute rehabilitation.

Mandating changes to cover comprehensive BI care for Medicare and commercial insurance plans, which are regulated by federal laws, would encounter significant logistical and legislative obstacles. The products most easily adapted to provide comprehensive BI care are Medicaid and the Brain Injury Service Fund Program, a short-term crisis interim program.

Other states have successfully created programs (so-called “BI waiver programs”) that mandate and provide funds for comprehensive BI care for Medicaid patients and unfunded patients. In addition to acute hospitalization and post-acute rehabilitation, these programs cover long-term community support services. Although NM through Centennial Care does technically have a pathway to apply for these long-term community supports, it is not specific to the needs of persons living with BI, it is challenging to apply for this pathway, there is little oversight of it, and there is a lack of personnel trained in BI care to provide these supports. New Mexico should invest in creating a separate and distinct BI waiver program for adult Medicaid and non-Medicaid patients.

At the present time, there is no New Mexico state registry that informs how many citizens sustain a BI each year and/or are living with BI. There are existing programs that conduct surveillance for BI at a population level, but these are fragmented. An integrated and comprehensive surveillance program and registry remains a major need to serve the citizens of New Mexico and for which there are well-established models elsewhere. Opportunities to fund a NM BI registry currently exist through federal government state demonstration grants, which New Mexico has successfully utilized previously. The State Department of Health should partner with local academic and advocacy groups to apply for funding to establish and maintain a BI registry.

Introduction: Vignettes of Lived Experience with Brain Injury

Many people may experience the same cause of a brain injury – a fall, a motor vehicle accident, a stroke. What is never the same, however, is what happens to each brain after it is exposed to that trauma. Some of us may walk away and, for the most part, be ok. Some of us may lose our jobs, our families, our hope. Some of us may never be able to live independently again.

Michael Martinez didn't know that his chronic pain, daily confusion, headaches, and sleepless nights were because of his brain injury. His wife and his boss didn't know either, and even the doctors missed the diagnosis. Soon his wife, his job, and his home would all be gone. He says it isn't their fault that he sleeps alone in his Camry with his brain injury. But it isn't his fault either.

Suzanna Davis still lived in her childhood home, with 10 acres of alfalfa in the South Valley surrounding her. It was fertile and vibrant. After her brain injury, she started forgetting to schedule the irrigation. The fields, along with her mental health, began to wilt. Her daughter tried to help, but Suzanna soon began to self-medicate with alcohol to try and control her depression and anxiety until nothing would grow there again. Everyone seemed to focus on the drug use, but not on the brain injury that led to it.

Leslie Anderson hid her brain injury like she hid the dimple in the wall where her head had hit. She had to, because if Frank suspected that she let anyone find out that he abused her, he'd do worse. A poster would cover the wall, but her headaches were making it harder and harder for her to read, threatening her dream of finishing college - her escape plan. She stayed with Frank and eventually hid it all behind that poster.

The police report said that a semi-trailer truck hit Carlos Emiliano at a speed of 70 miles per hour as he tried to fix a flat tire on the shoulder of I-25 between Hatch and Las Cruces. Carlos doesn't remember the accident at all. From his bed in Denver, Colorado, all Carlos knows is that he isn't home. Communicating is hard, walking is even harder, so most days he stays in bed, just not his bed.

"Google brain injury help New Mexico," is what Jess Steinmann yelled far too loudly at the town hall meeting. "It's all just a list of the places who haven't been able to help me!" The city council members adjusted in their seats. The chair said something about there being a state program. "Look for the Brain Injury Service Fund," he said. But Jess had already graduated from the fund eight years ago, and did not qualify for Medicaid.

Andrea Galilahi was a NM educator and voted Teacher of the Year. She watched her life dissolve after slipping on water at work, hitting her head and losing consciousness. Andrea had a second concussion less than a week later. Drea could no longer teach – which was her passion – and after months of frustration trying to obtain necessary work accommodations, she was admitted to a psychiatric hospital after a suicide attempt.

Melissa Begay was 17 when she flew off the back of the ATV and landed in a coma. Two months went by, and her family celebrated her 18th birthday at her bedside. Melissa's parents were told that she was no longer eligible for the programs, treatments, or therapists identified by her pediatrician to provide the best plan of care. "What is she eligible for then?" her mom asked. But the system for adult long-term care is complex, and they always seemed to hit roadblocks, to the point that they gave up.

Each of these accounts is a minute, hypothetical representation of daily life for the thousands of people living with or caring for someone with a brain injury in New Mexico. The reality is much more dire. Left undiagnosed, untreated, or unsupported, a brain injury can easily lead to a systemic assault and annihilation of a whole person and life, making it impossible to stay employed or heal. We as New Mexicans should all know we are and will be supported in the recovery and rehabilitation from a brain injury by a network we aren't forced to navigate while brain injured. We should all have a chance to get better.

Key Findings and Recommendations

Key Finding #1: Brain injury care is specialized and requires a coordinated system of care with specific therapeutic components.

Rationale: An acquired brain injury (ABI) is the umbrella term for injury to the brain that is not hereditary, congenital, degenerative, nor induced by birth trauma. (<https://www.biausa.org/brain-injury/about-brain-injury/nbiic/what-is-the-difference-between-an-acquired-brain-injury-and-a-traumatic-brain-injury>). It includes non-traumatic brain injury etiologies such as stroke, infection (e.g., encephalitis), intracranial tumor resection, hypoxic ischemic brain injury after cardiac arrest, and others in addition to traumatic brain injury (TBI). While this report focuses at times on TBI in New Mexico due to the availability of prior data and programs focused on TBI, it is essential that future service provision and funding considerations ensure that services for all types of brain injuries (BI) are covered. This is reasonable and feasible in that many of the post-acute symptoms including physical, emotional, and cognitive disabilities that present following TBI are shared across the ABI spectrum, meaning that rehabilitation programs set up for TBI have the potential to benefit the entire ABI population.

TBI severity is defined by standardized criteria, including loss of consciousness (LOC) duration, post-traumatic amnesia (PTA) duration, and initial Glasgow Coma Scale (GCS; eye opening, verbal communication, motor) score. As TBI severity increases along with LOC and PTA duration while the GCS measures TBI severity is classified according to severity as mild, complicated mild, moderate, or severe. Initial TBI severity informs prognosis for post-injury mortality, morbidity, and disability (1).

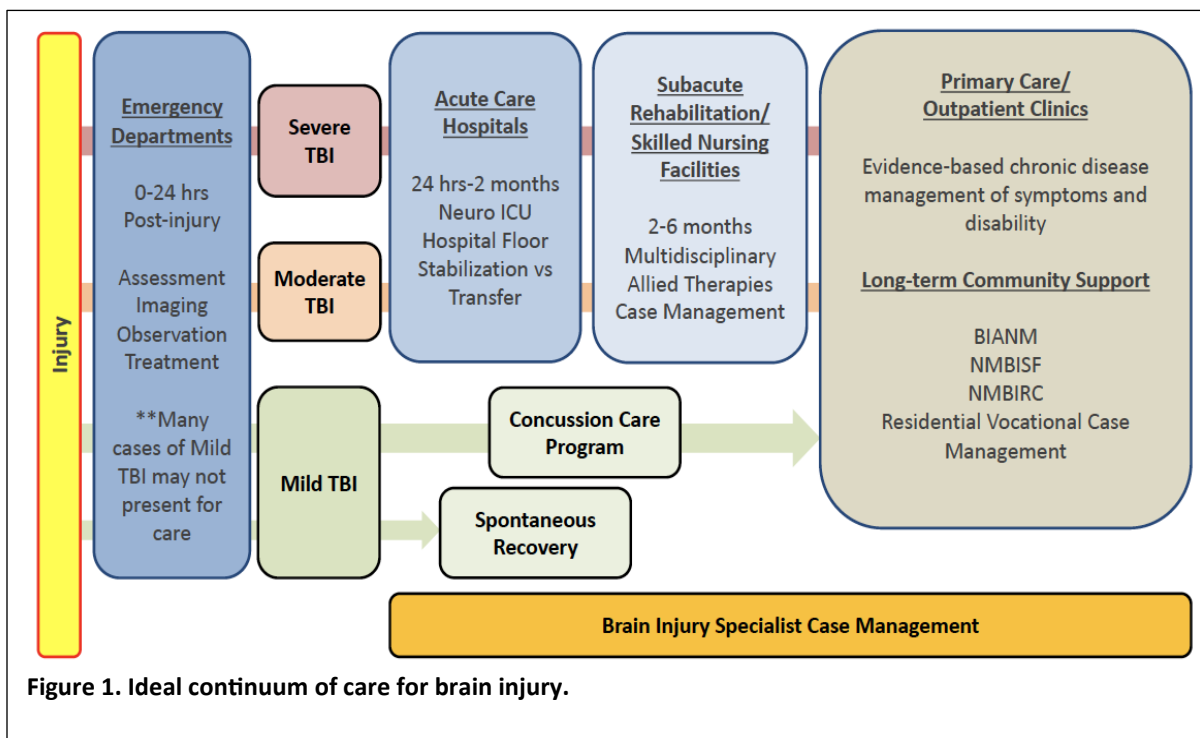


Figure 1. Ideal continuum of care for brain injury.

The continuum of care for BI is well-established and is composed of four phases or components (see Figure 1): stabilization in the acute hospital setting, subacute rehabilitation or skilled nursing care, outpatient ambulatory care, and community integration and support. These components are not mutually exclusive, and may occur simultaneously, sequentially, or intermittently. Ideally, there is non-fragmented and smooth transition from one care component to the next, with overarching case management occurring throughout all phases to ensure appropriate continuity of communication, services, and resources. However, the needs of persons with differing levels of TBI severity vary substantially from person-to-person, as do associated co-occurring physical injuries and pre-injury medical, neurological, psychiatric, substance use, and other health and social factors. As a result,

persons living with TBI often also receive care in long-term acute care facilities, skilled nursing facilities, post-acute neurobehavioral rehabilitation facilities, and residential care facilities. Integration of care with other medical services, both inpatient and outpatient, as well as community-based rehabilitation, vocational, support, life skills, and independent living support services are needed by persons with moderate or severe TBI.

The complement of services that are included in an optimal comprehensive system of TBI care are described clearly and usefully in the Ontario Neurotrauma Foundation (ONF) comprehensive guidelines for the rehabilitation of adults with the full spectrum of TBI (2). In addition to emergency department and acute hospital services that provide evidence-informed TBI care, the components of a comprehensive system also include:

- 1) Inpatient and outpatient rehabilitation services (e.g., intensive care, physical therapy, occupational therapy, speech/language therapy, cognitive therapy);
- 2) Specialty services for persons with disorders of consciousness (e.g., coma, unresponsive wakefulness syndrome, minimally conscious state);
- 3) Subacute rehabilitation, whether in as part of a long-term acute care, skilled nursing, or post-acute neurorehabilitation facility;
- 4) Residential care services;
- 5) Community-based services that promote reintegration and participation;
- 6) Caregiver and respite services
- 7) Services for caregivers and families;
- 8) Brain injury education and awareness services;
- 9) Legal, housing, and other public services needed to support comprehensive rehabilitation, e.g., independent living centers;
- 10) Centralized, flexible, and convenient access points for the system of care.

Ideally, this complement of services is available and provided in the area in which a person with BI and their family live.

Recommendation: A well-established, evidence-based system of care for brain injury should form the basis for recommendations regarding brain injury services.

Key Finding #2: Lack of coverage for a brain injury system of care leads to lower rates of recovery, increased disability, increased rehospitalization and institutionalization, and increased societal costs.

Rationale: BI is not just an event, but a chronic condition that affects every domain of a person's life. According to the TBIMS National Database study by Brooks et al. (3), 43% of hospitalized patients with moderate-severe TBI have a significant disability at 1 year after injury. In patients whose TBI is severe enough they require inpatient rehabilitation, they go on to experience worsening function and quality of life five years or more after injury, despite the significant improvements they may have accumulated through the first several years. Factors such as older age, non-White race, lower preinjury productivity, public payer source, longer length of inpatient rehabilitation stay, and lower discharge functional status were found to negatively impact trajectories of change over time (4). Of note, New Mexicans with BI fall disproportionately into these vulnerable groups. In a study of 404 persons living with TBI in the TBIMS National Database, multiple medical and behavioral comorbidities were associated with worse functioning over time (5). There is a decrement of functioning in a third of all patients with moderate-severe TBI by 10 years post-injury (6). Patients with moderate-severe TBI also go on to experience shortened life span after their injury and were 2.23 times more likely to die than individuals of comparable age, sex, and race in the general population, with a reduced average life expectancy of nine years.

In persons experiencing mild TBI or concussion, there can be increased risk of long-term impairment and disability (up to 30%)(7) if standard care is not received at time of injury, including accurate diagnosis, education about symptom management, advisement on return to work/play/learn, and access to BI specialty care. There can also be a deleterious interaction between BI and the workplace setting: BI not only can lead to temporary or permanent inability to work but having to navigate onerous bureaucratic and regulatory procedures to receive appropriate accommodations, resources, support, and treatment can impede BI recovery.

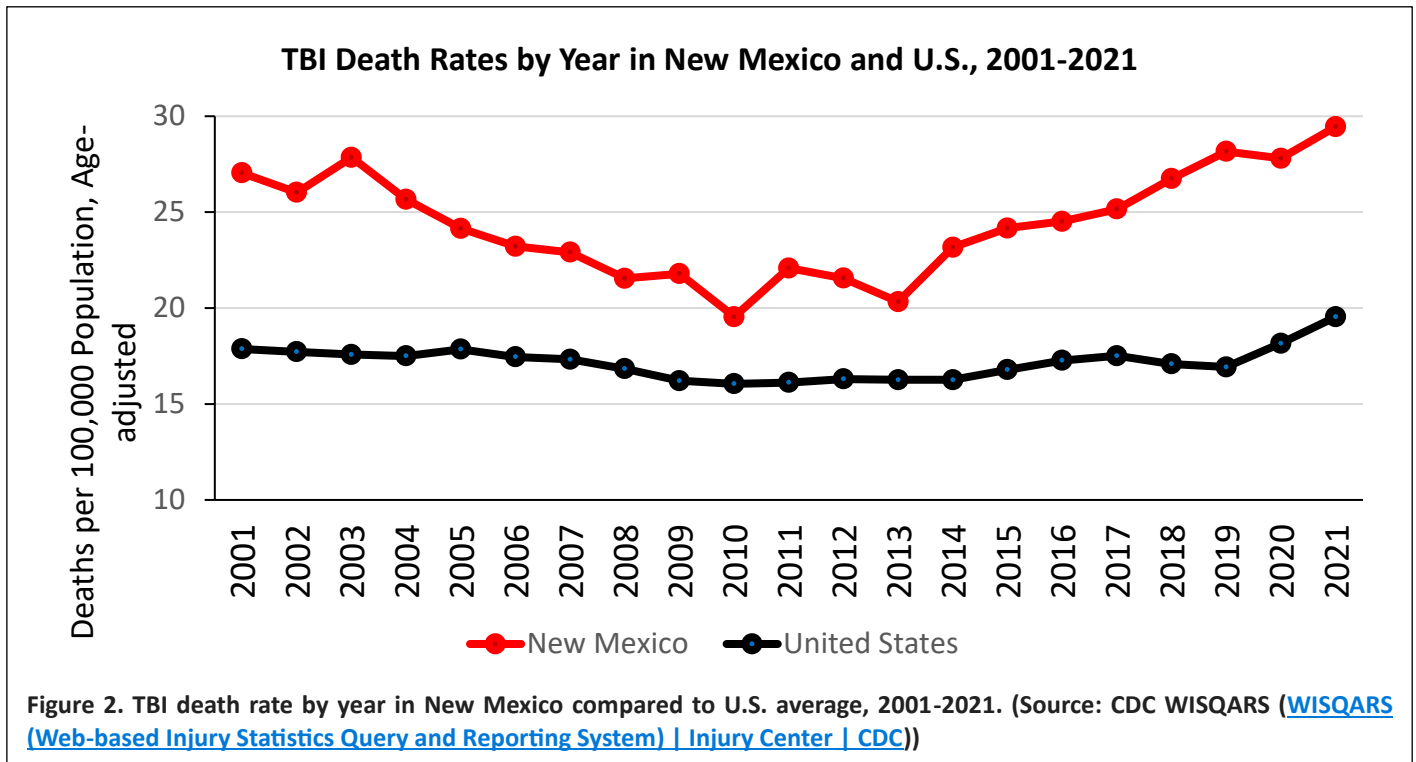
There is thus significant evidence pointing toward the need for long-term ongoing management of BI-related symptoms and complications, as well as management of physical and mental health comorbidities. Not only do chronic comorbidities in persons living with BI have negative effects on long-term functioning, but they also lead to increased costs associated with care. In a study of 3756 subjects in a health maintenance organization database age 15 and older (939 patients with TBI and 2817 patients without), average costs were 76% higher in the 3 years after injury for the mild TBI group, and 5.75 times greater for the moderate-to-severe TBI group compared to controls (8). The presence of psychiatric illness was associated with more than doubling of total costs for both inpatient and outpatient non-mental health care. BI and psychiatric illness were each associated with significant increases in health care costs; those with the combination of moderate-to-severe TBI and psychiatric illness had much higher costs than any other group. Over the lifespan, BI can influence diseases of old age, and increases long-term risk of development of dementia.

Insurance coverage is an important factor in whether a patient with BI goes on to receive subsequent rehabilitation. First, there is a significant body of literature that demonstrates that patients with TBI who are uninsured or underinsured are less likely to be scanned for brain trauma on initial presentation, more likely to stay in the acute care hospital longer, and are less likely to be transferred to an inpatient rehabilitation facility following acute hospitalization (9–12) Second, inability to access standard of care multidisciplinary BI rehabilitation programs has been associated with greater levels of long-term disability and increased costs to society (9,11,13,14). Finally, programs such as state BI waivers focused on providing community-based supports and services in place of institutionalization have been studied and shown to reduce long-term costs of care for individuals with BI (15–19).

Recommendation: The State of New Mexico should formally adopt an evidence-based brain injury system of care to increase access to services, reduce disability, improve the quality of life of its citizens, and reduce costs to the state.

Key Finding #3: NM has a high burden of brain injury disability, but data describing this is lacking.

Rationale: The frequency of lethal TBI among New Mexicans is described well in the three previously commissioned reports on TBI in New Mexico (20–22). TBI occurs frequently in New Mexico, and deaths from TBI are disproportionately high in our state (see **Figure 2**). The first report published in 2010 highlighted the significant health consequences of TBI for New Mexicans: among 34 states, New Mexico ranked second-highest in annual TBI deaths per capita (20). A follow-up report in 2012 updated these statistics (21), and a third report in 2019 demonstrated a significant year-over-year increase in TBI deaths per capita between 2012 and 2016, far exceeding the national average (26 per 100,000 compared to 18 per 100,000 nationally). Particularly noteworthy was an increase in TBI mortality rate during the last five years (22). TBI kills more New Mexicans per year than opioid overdoses (25.5 deaths per 100,000 for TBI in 2016; 23.1 per 100,000 for opioid use in 2015-2019)



(22)(23).

Unfortunately, information on TBI-associated disability in New Mexico is not publicly available or readily accessible, highlighting the need for a TBI registry. The number of persons living with TBI-related disability in New Mexico can be estimated using regional or national observations and reports to inform those estimates. In a survey of 2,701 adults in Colorado, "up to 42.5% of respondents reported a lifetime history of at least one traumatic brain injury. Multiple negative outcomes were found to increase in prevalence . . . with greater TBI severity." According to Selassie et al. (24), the incidence of long-term disability following TBI hospitalization is approximately 43%. Between 2004 and 2016, 16,186 New Mexicans were hospitalized with a TBI. In other words, 1,349 people had TBI-associated hospitalizations each year. If 43% of these individuals can reasonably be expected to develop long-term disability thereafter, then approximately **580** New Mexican develop TBI-associated long-term disability each year.

While TBI requiring hospitalization and inpatient rehabilitation is associated with an average life expectancy reduction of 4-7 years (25), the average 25-year-old can expect to live 55 additional years after TBI (26). The CDC estimates that 3.3-5.3 million people (about 1-1.5% of the population) in the United States are living with disability after TBI (21,27). These estimates integrate information derived from the National Hospital Discharge Survey in the late 1990s, the seminal work of Zaloshnja et al. (28), and the Colorado TBI Registry and Follow

Up System described by Brooks et al (3). Applying these TBI-associated disability prevalence estimates (i.e., 1-1.5%) to the US Census Bureau reported New Mexico population of 2.12 million persons (as of April 1, 2020) (29), there are between **21,000 and 32,000 New Mexicans presently living with TBI-associated disability.**

It is important to note that vulnerable communities in New Mexico face the worst health outcomes after a TBI. Those most likely to be hospitalized due to a brain injury are Native Americans, the elderly, and infants under four years of age. Compared to their urban counterparts, persons living with TBI in remote rural areas have worse outcomes across a variety of functional domains, as well as poorer health and quality of life months-to-years after injury (30,31).

Native Americans: When compared to other populations, TBI hospitalization and death rates are greatest among Native

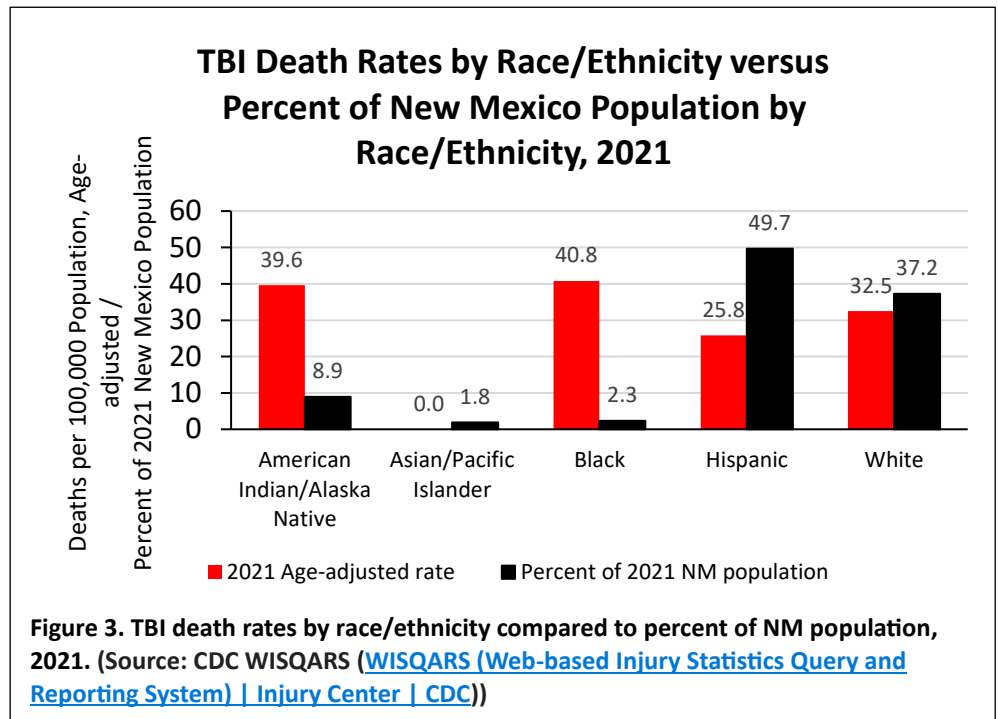
Americans/Alaska Natives at any age. According to the CDC, Native Americans in the 0-64 age group represented 8 percent of patients with TBI on first time admissions, as compared to 14 percent for Whites and yet, Indigenous people only represent 1 percent of the population as compared to 50 percent for Whites. (<https://www.cdc.gov/traumaticbraininjury/health-disparities-tbi.html>). The state TBI lethality data (see Figure 3) also capture the disproportionate impact on Native Americans.

Foster care: Several studies show that about two-thirds of young people between the ages of 16 and 29 currently in or with a history of being in foster care report that they have sustained one or more TBIs (32–34). Vulnerable participants tended to report markedly higher rates of TBI and adverse childhood events than healthy controls.

Substance use: There are high rates of TBI in persons with substance use disorders. The contribution of head injuries to neuropsychological deficits was studied in 157 recently detoxified alcoholics and 400 control subjects consisting of age-stratified randomly selected men and women from the same geographical area as the alcoholics. Head injuries had occurred in 41% and 22% of the male and female alcoholics, but only in 15% and 6% of the male and female control subjects (35). Malloy et al in 1990 found 58% of a sample of 30 alcoholics had TBI marked by loss of consciousness, hospitalization, or major neurological change (36)

Domestic Violence: Persons who are victims of domestic violence have a high rate of BI which is often unrecognized and undiagnosed by law enforcement (37,38) Ninety-nine battered women were assessed using neuropsychological, psychopathology, and abuse history measures. Almost three quarters of the sample sustained at least 1 partner-related BI and half sustained multiple partner-related BIs. Further, in a subset of women (n = 57), BI severity was negatively associated with measures of memory, learning, and cognitive flexibility and was positively associated with partner abuse severity, general distress, anhedonic depression, worry, anxious arousal, and posttraumatic stress disorder symptomatology (37).

Homeless/Unhoused: The prevalence of BI in homeless and marginally housed individuals is very high. In a systematic review and meta-analysis of 22 studies, the lifetime prevalence of any severity of TBI in homeless and



marginally housed individuals (18 studies, n=9702 individuals) was 53.1% and the lifetime prevalence of moderate or severe TBI (nine studies, n=5787) was 22.5% (39). TBI was consistently associated with poorer self-reported physical and mental health, higher suicidality and suicide risk, memory concerns, and increased health service use and criminal justice system involvement.

Incarceration: Twenty-five to 87% of inmates in US prisons and jails have experienced a TBI at some point in their lives (https://www.cdc.gov/traumaticbraininjury/pdf/prisoner_tbi_prof-a.pdf), compared to 8.5% occurrence in the general public. There is currently no data on the prevalence of TBI in the incarcerated population of New Mexico. As TBI can cause increased disinhibition, impulsivity, and aggression, appropriate evaluation and treatment of TBI in this group would likely have benefit for reducing recidivism and improving re-integration into society.

Recommendation: The State of New Mexico should recognize brain injury as a public health issue as serious as opiate use and obtain accurate data about brain injury-related disability in New Mexicans.

Key Finding #4: New Mexico has a fragmented system of brain injury care, with several components not well integrated, not well coordinated, or missing.

Rationale: New Mexico currently does not have a comprehensive system of BI care. This is a significant failure that results in increased costs for the state and significant burden on persons living with BI and their families who must make living, working, and transportation arrangements in different states to enable this rehabilitation to occur.

A comprehensive system of BI care should be based on evidence-based BI guidelines and make them easily available to all stakeholders. The cultural, geographical, and financial considerations of New Mexico are likely to require substantial modification of these guidelines. However, the state's history of innovation, creativity, and resourcefulness in delivering healthcare to persons in rural and remote areas is an area of identified strength. The models of systems of care that have been constructed and subsequently published share common elements, components, and themes. New Mexico can easily and flexibly adopt one of these models to act as the scaffolding for a state-wide system of care. Having the ability to provide BI-specific care in a patient's home community through their primary care provider would be a significant step in a positive direction. Training and education, provided through state- or institution-sponsored didactic programs, would empower and equip providers to deliver this care to patients without needing to travel long distances for consultations with specialists.

Please refer to the diagram from **Key Finding #1** describing the elements of a comprehensive system of BI care.

Emergency Departments/Acute Care Hospitals/Trauma Centers: **Not Adequate**

Several pieces of the continuum of BI care are relatively well-represented in New Mexico, such as emergency services, and hospital-based acute care. Please see prior the DOH TBI reports for more details (20,22) However, there is a need for improved training and awareness for emergency providers on the diagnosis of BI and measures to reduce long-term disability after concussion, such as return to work/learn/play guidelines, education materials for patients, and access to specialists. There is also no clear central service hub that providers or patients can easily access to obtain BI care, which can lead to increased and excess use of emergency services.

Subacute Rehabilitation/Skilled Nursing Facilities (SNF): **Not Adequate**

With regard to subacute care, there are four hospital-based rehabilitation wards, with a total of 230 beds. Of 810 patients admitted to UNMH with BI, 174 were discharged to inpatient rehabilitation (21%). With an average of 1300 annual hospitalizations for BI statewide, it is reasonable to estimate that approximately 270 patients hospitalized with BI in New Mexico will need transfer to a rehabilitation facility over the course of a year. While there are inpatient rehabilitation facilities (IRF), long-term acute care facilities (LTAC), skilled nursing facilities (SNF), post-acute rehabilitation, residential nursing and other services for persons with BI, these are not currently part of a well-integrated system in New Mexico. There is also no dedicated neurological rehabilitation center in New Mexico. This is despite a significant percentage of patients each year requiring skilled nursing facility or inpatient rehabilitation level of care following their acute hospital stay with significant neurotrauma. All other states in the Southwest/Mountain West region have dedicated neurological rehabilitation centers. As a result, New Mexicans are transferred out of state to Texas, Oklahoma, or Colorado when they require specialized neurological or neurobehavioral rehabilitation.

Primary care/Outpatient Clinics: **Not Adequate**

It is a common complaint among New Mexicans reporting symptomatic BI that there is little to no expertise or guidance for their primary care providers to deliver standard of care treatment for BI. Furthermore, there are not enough clinicians who are knowledgeable enough to diagnose a patient with a BI, which is an important requirement for patients to meet to obtain services. Lastly, few providers understand the intersection of BI with disability laws, which can render persons living with BI more vulnerable to ADA violations, job loss, and inadequate assistance. A solution that has been utilized to address similar gaps in care in other diseases is the Project ECHO model. In a Brain Injury ECHO, the Clinic hub team will be composed of study team members

who are subject matter experts in BI, and will be supported by a highly experienced ECHO implementation team. Each ECHO session will consist of a didactic presentation, and de-identified patient case presentations, delivered by spoke team members. This model enables PCPs and community providers to participate in a collaborative, team-based approach to learn the BI care model, manage their patients with BIs according to the model, and receive specialist-level guidance on tailoring the model to individual situations.

Long-term Community Support/Concussion Care/Brain Injury Case Management: Not Adequate

While there are several organizations and entities focused on advocacy and support for persons living with BI, such as the Brain Injury Alliance of NM, and ARCA/NeuRoads, they cannot meet the need for services given the estimated volume of persons disabled by BI. There are not enough trained allied health specialists, therapists, case managers, social workers, and caregivers who can work with persons with BI and provide the specific interventions and support that are needed.

Trained personnel are needed to support a comprehensive, integrated BI system of care. While New Mexico has several training programs that serve this purpose, outlined below, these are not extensive enough nor integrated well enough, and would benefit from support and expansion.

- a) **CBIS Training Programs**: An important program for increasing a state's capacity and level of expertise in caring for persons living with BI is the formal training to become a certified brain injury specialist, known as ACBIS. Individuals trained by ACBIS would be especially suited for providing the kind of BI-specific case management and intensive support that patients with moderate-severe illnesses require.

- b) **Brain Injury Fundamentals Course**: [Information & Eligibility - Brain Injury Association of America \(biausa.org\)](http://biausa.org): Developed by experienced clinicians and rehabilitation professionals, Brain Injury Fundamentals is a training and certificate program designed to address the unique needs and challenges of those who care for or encounter individuals with BI. This includes non-licensed direct care staff persons, facility staff, family members and friends, first responders, and others in the community. The training course covers essential topics such as cognition; guidelines for interacting and building rapport; BI and behavior; medical complications; safe medication management; families coping with BI.

The course is grounded in adult learning principles, maximizing participant engagement and application through an interactive workbook. Using real-life scenarios to anchor the course concepts, participants learn about the challenges people face following BI and the types of support they need. This essential program will help candidates understand different types of behavior, manage medication safely, and provide support to families and friends. After completing intensive training, candidates will receive a certificate that is valid for three years.

- c) **Integrated Cognitive Rehabilitation Psychotherapy (ICRP) Training Program**: ICRP is a culturally sensitive model of therapy developed in New Mexico for treatment of persons living with BI. Traditional therapy works very well in treating people living with trauma, mood disorders, and substance use. A high proportion of people living with BI are in need of care for trauma, behavioral health and substance use issues, but BI is not identified or addressed in treatment. ICRP integrates the treatment of psychosocial and substance use issues with treatment of cognitive deficits using restorative and compensatory strategies. An important component of ICRP is the application of an interdisciplinary or transdisciplinary model in setting goals and objectives across co-occurring issues and the simultaneous treatment of several co-occurring issues by a team of providers. Working through stages of recovery in developing appropriate goals and objectives and accommodations for cognitive issues across interventions is essential to engagement in therapy and good outcomes. ICRP is taught

in an online tele-mentoring clinic to therapists working with persons living with BI by medical director Mark Pedrotty, Ph.D..

- d) Brain Injury Care Network of New Mexico (BICNNM): The Brain Injury Advisory Council (BIAC) to the Governor's Commission on Disability (GCD) funded the development of this care network by the Brain Injury Alliance of New Mexico. This initiative has provided brief, introductory training to small proportions of health care providers, first responders, and front-line staff of domestic violence shelters. Educational videos targeting these three groups are now available online at <https://www.braininjurynm.org/brain-injury-care-network/>. These videos provide an overview of identification and management of BI. This network needs to be built out so that all health care providers, first responders, and DV shelter workers receive ongoing training in care for those living with BI.
- e) Family/Caregiver Education: Effective communication with the BI community is essential for being able to gather feedback to improve healthcare delivery. An educational series that is oriented toward patients and families would be a huge help for them as they navigate the turbulent times and unfamiliar landscape following a BI event. That transition from acute care to subacute care, with up to 40% going home, another 30% going to SNF or inpatient rehabilitation, comes at a crucial time for bridging information and community support.

In addition to training specialists to provide community support services for persons with BI, additional components and resources for a comprehensive BI system of care are needed but are currently scarce or missing altogether:

- f) Support Groups: Support groups assist in connecting the person living with BI to others who may be experiencing similar challenges so they don't feel so alone. Support groups also help families create networks of support and provides a platform for professionals to connect to the community. Potential examples include clinically-led support groups for children whose parents are living with BI; domestic violence survivors living with BI; conditions co-morbid with BI; and caregiver support groups. There are several support groups in NM, but they are needed in every area of the state.
- g) Vocational Rehabilitation: One of the most frustrating aspects for persons living with BI is the perceived lack of possibilities for vocational training and preparation to re-enter the work force. The efforts of the Department of Vocational Rehabilitation are greatly appreciated, especially for patients with injuries toward the severe end of the spectrum who often cannot manage the rigors of a typical job and may have little activity to occupy them. Programs oriented toward BI specifically, staffed with trained providers, help to provide structure and purpose for this population.
- h) Provider Training: There is a need for education and training for providers to screen for and make diagnoses of BI in vulnerable populations such as domestic violence victims, substance users, and incarcerated persons.
- i) Self-Help: Educational material needs to be provided to people living with BI and their families on resources and practices that contribute recovery so they can take a pro-active role to relieve anxiety and manage depression. These include but are not limited to: meditation; mindfulness-based relapse prevention; tai chi; emotional freedom techniques (e.g., tapping); EMDR; nutrition; exercise; art; music; spirituality; other practices.
- j) Supportive Housing/Transitional Housing: as previously described, there are very high percentages (>50%) of the homeless/unhoused population with BI. Individuals with disabling BI are also more likely to become unhoused after their injury. Yet it is difficult to define scope of the problem, as there

are no data on how many unhoused individuals with BI there are in NM. There is also significant overlap with the incarcerated population, where rates of BI can be as high as 80%. It is apparent that unhoused individuals with BI will have more difficulties with all components of BI care, including accessing care/getting to appointments, timely discharge from hospital, rejections from subacute facilities (none want to get “stuck” with a patient with nowhere to be discharged to), getting guardianships/POA due to lack of family support, and inability to access outpatient/community rehabilitation components due to lack of money, transportation, or a place to store medications.

- k) Access Hub/Care Framework: Navigating a BI system of care can be significantly challenging if not impossible for persons living with BI who have cognitive deficits. A clear, simple Access Hub or System Framework is crucial for enabling persons living with BI to engage with and obtain the services they need. Care coordinators or navigators must be trained to work with persons living with BI so that they understand the challenges that may delay or derail their clients’ efforts to obtain services.

Recommendation: The State of New Mexico should improve the components not well established in the current system of care for brain injury, through the following:

- 1) **Train a brain injury informed workforce,**
- 2) **Establish a dedicated neurorehabilitation facility,**
- 3) **Support a Brain Injury ECHO program to improve access to specialists,**
- 4) **Provide services and supported housing specifically for persons living with brain injury,**
- 5) **Establish a clear, convenient access hub or brain injury system framework.**

Key Finding #5: Medicare and commercial insurance plans cover critical BI care components to varying degrees, but are not feasible to amend in a timely fashion as they are governed by federal regulations.

Rationale: The federal Affordable Care Act requires all major medical health commercial insurance marketed to individuals and small groups to cover a standard group of benefits. This standard group of benefits is called a "benchmark" plan. The ACA requires states to set this benchmark plan based on popular existing health plans. The actuarial value of this benchmark plan is then used to calculate the premium tax credits consumers will receive from the federal government to help subsidize purchasing coverage through the health insurance marketplace.

To limit the amount the federal government would be required to pay for premium tax credits in any given state, the Affordable Care Act requires states to defray the costs of any newly mandated benefits. Newly mandated benefits are any legislatively or administratively mandated benefits in excess of the benchmark and any benefits not mandated by the state prior to the passage of the ACA (see 42 U.S.C.A. § 18031 and 45 CFR §155.170; <https://www.cms.gov/CCIIO/Resources/Files/Downloads/ehb-faq-508.pdf>).

The Centers for Medicaid and Medicare (CMS), Center for Information and Insurance Oversight (CCIIO), are responsible for overseeing the federal government's regulation of the ACA's essential health benefits and advance premium tax credits laws. CCIIO staff has stated that any state law that clarifies a currently broadly worded benefit mandate to include more specific benefits would be considered a new benefit mandate pursuant to 42 U.S.C.A. § 18031 and its current regulations. As a result, any legislative coverage mandate with more specific language mandating BI coverages and services would require a cost defrayal payment to the federal government. OSI cannot change the benchmark plan through regulation pursuant to federal actuarial rules.

The Office of the Superintendent of Insurance would have to work with a contract actuary to annually determine defrayal costs for these benefits and assist with federal reporting. OSI projects that the cost of these contractual services would be approximately \$150k annually. This is an annual cost only to determine the actual defrayal costs. The annual defrayal costs would vary each year depending on the services utilized, but the annual cost could easily be in the millions. Any legislative coverage mandate would need to come with an annual appropriate sufficient to cover the affiliated costs.

Recommendation: The State of New Mexico should defer seeking to change Medicare or commercial insurance coverage of brain injury care at this time.

Key Finding #6: Medicaid and non-Medicaid programs are under greater state control and there is a clear and established process for creating a Brain Injury Waiver program, as multiple other states have done.

Rationale: The National Association of State Head Injury Administrators (NASHIA) has written about the Medicaid TBI/ABI Home and Community Based Services waiver programs (<https://www.nashia.org/resources-list/col0j7vwe0nza4wmvddbvmxfaq65n>), from which the following information was taken.

Federal Medicaid program mandates certain benefits that have to be offered, including:

- 1) Inpatient hospital services
- 2) Outpatient hospital services
- 3) Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT)
- 4) Nursing facility services
- 5) Home health services
- 6) Physician services
- 7) Rural health clinic services
- 8) Laboratory and X-ray services
- 9) Transportation to medical care

States may offer additional services or benefits, known as optional services, and these include:

- 1) Diagnostic services
- 2) Case management
- 3) Prescription drugs and prosthetic devices
- 4) Clinic services
- 5) Intermediate care facilities for individuals with intellectual disabilities (ICF-IID)
- 6) Optometrist services and eyeglasses
- 7) Rehabilitation
- 8) Therapy services
- 9) Transportation services
- 10) Inpatient psychiatric hospital services for individuals under the age of 21
- 11) Home and community-based waiver programs
- 12) Personal care services

Long-Term Services and Supports Options

Medicaid is the primary payer of long-term services and supports (LTSS). The U.S. Supreme Court's 1999 landmark decision in *Olmstead v. L.C.* resulted in increased Medicaid options to assist States in offering community-based services in lieu of institutional services. States have the following options for LTSS:

1915 (c) Home and Community-Based Services Waivers

The Home and Community-Based Services (HCBS) waiver program was established under section 1915(c) of the Social Security Act of 1981. The purpose of this provision is to offer a broad range of home- and community-based services to people who may otherwise be institutionalized. This option allows States to waive certain Medicaid program requirements, including:

- 1) Stateness: Allows States to target waivers to areas of the State where the need is greatest, or where certain types of providers are available.
- 2) Comparability of services: Allows States to offer waiver services to only certain groups of people who are at risk of institutionalization, such as BI.
- 3) Income and resource rules applicable in the community: Allows States to provide Medicaid to people who would otherwise be eligible only in an institutional setting, often due to the income and resources of a spouse or parent.

State HCBS Waiver programs must demonstrate cost neutrality; ensure the protection of people's health and welfare; provide adequate and reasonable provider standards to meet the needs of the target population; and ensure that services follow an individualized and person-centered plan of care.

To be eligible for a waiver program, a person must meet the State's Medicaid and waiver eligibility criteria and require an institutional level of care (nursing level of care) as assessed by the State. Services provided by the waiver are to be above and beyond the services otherwise offered by the State Medicaid program.

TBI/ABI HCBS Waiver Programs

Twenty-one States administer TBI/ABI waiver programs with three States administering more than one TBI/ABI waiver (CT, KY, MA). Most States have designed their waiver programs around typical LTSS services. However, a handful of States have designed their waiver services to focus primarily on short-term rehabilitation and community reintegration. Most states base their level of care waiver requirements and project cost savings based on care provided in a nursing facility.

As states are responsible for assessing level of care, functional assessment tools and evaluation varies with each State and even with regard to each waiver program that the State administers (i.e., IDD, physical disabilities, aging, or autism). Understanding how functional assessments are performed is critical in determining needs and eligibility for HCBS waiver programs. These assessments may be performed by personnel from a state agency or through contracted agencies. Once a person is assessed and determined to be eligible, a comprehensive service plan (personal care plan) will be developed generally by an interdisciplinary team, service coordinator/case manager, other support programs/resources/providers, the individuals with a TBI, and any others that the individual with a TBI may choose.

Most services covered under TBI/ABI HCBS Waiver programs include adult day care, personal assistant, case management, cognitive rehabilitation, homemaker, home and vehicle modifications, durable medical equipment, therapies, behavioral programming, family counseling, respite, prevocational services, supported employment, and personal emergency response systems. Waiver participants must have full access to State Plan services. Waivers cannot cover room and board, however. In many States, a non-Medicaid agency may be responsible for administering the program aspects of the waiver program, while the Medicaid agency is responsible for submitting the waiver and general oversight.

Considerations for Pursuing a TBI/ABI Waiver

Medicaid waivers are exceptions to the State's Medicaid Plan services and must be above and beyond what is currently provided. Other areas to consider include:

- 1) What are the current facilities where individuals with BI are receiving LTSS and to what extent? A State may want to conduct a survey to determine how many people are residing in institutional settings and the associated costs for that care.
- 2) What is the purpose of the waiver?
- 3) Which of the Medicaid requirements will be waived (i.e., statewide, comparability of services, freedom of choice)?
- 4) How will the waiver be administered and operated and by whom? Who will provide oversight to ensure quality of care, including systems to effectively monitor the adequacy of service plans, the qualifications of providers, and the health and welfare of beneficiaries? In some States, it rests with the Medicaid agency and in other States, responsibilities are split with another agency responsible for service delivery for the population to be served.
- 5) Does the level of care assessment tool distinguish between being able to perform tasks independently with or without cues or prompting in order to perform activities of daily living (ADLs) and Instrumental Activities of Daily Living (IADLs)?
- 6) What is the scope of services or limitations, delivery methods and rate?

- 7) What additional services are needed beyond the State Medicaid Plan to provide the level of supports to enable an individual to live in the community (e.g., housing)?
- 8) Who are the providers that will be needed to carry out the community services -- what type of providers, their qualifications (credentials/licensure), and expertise?
- 9) What financial information is needed to demonstrate cost neutrality?
- 10) What general fund match is needed for the creation of a new BI waiver?
- 11) Can services be covered under an existing waiver that may be amended?

Recommendation: The State of New Mexico should create and designate a Medicaid Brain Injury Waiver program, staffed by personnel who are trained and knowledgeable in brain injury, under which persons living with brain injury can qualify for and receive brain injury-specific long-term care.

Key Finding #7: NM Medicaid through the Centennial Care program has an organized program of community support that provides many of the components that should be covered for persons living with BI but is not specific enough or comprehensive enough to meet their needs and is underutilized by patients and providers.

Rationale: The 1115(c) Medicaid Waiver, known as Centennial Care, comprehensively integrates the physical and behavioral health needs of those on State Medicaid programs. Centennial Care began January 1, 2014 and services are provided by three managed care organizations (MCOs). These services include physical health, behavioral health, long-term care and community benefits. There are currently two tracks for waiver programs in New Mexico (<https://www.hsd.state.nm.us/lookingforassistance/centennial-care-overview/>):

Track 1: 1915(c) Home and Community Based Services (HCBS) Developmental Disabilities waiver programs” which include the Developmental Disabilities Waiver, Mi Via self-directed waiver, and the Supports Waiver for children and adults with developmental disabilities.

Track 2: “Community Benefit” for people who are considered elderly or disabled (in any way), meet a nursing facility level of care but are receiving the services at home (<https://www.hsd.state.nm.us/community-benefit-program/>).

Prior to 2014, there was a waiver program that included persons living with BI. All those participants rolled into the Centennial Care Community Benefit, or into Mi Via if they had DD. In 2014, 267 people were grandfathered in. These individuals access their services through the Community Benefit, but those in the BI waiver prior to 2014 maintain their Brain Injury Category of Eligibility as long as they remain eligible and renew in a timely fashion. As of September 2023, 149 members remain in this Category of Eligibility.

The comprehensive long-term care benefit includes care coordination, HCBS services and personal care for 65 and older and adults 21 and older with disabilities, including individuals with BI previously served under the brain injury HCBS waiver, then under the Mi Via HCBS waiver. Level of Care assessments for Centennial Care consider degrees of cognitive impairment and include a Self-Directed and Agency-Directed Community Benefit for individuals with BI, previously served under Mi Via, as well as the Agency-Based Community Benefit.

The service package includes: adult day health, assisted living, behavioral support, community transition, customized community supports, emergency response, employment supports, environmental modifications, family supports, home health care aide, homemaker/personal care, nutritional counseling, peer support, private duty nursing for adults, related goods, respite, skilled maintenance therapy, SLT, PT, OT, specialized medical equipment and supplies, and specialized therapies, including cognitive rehabilitation.

Table 1. Comparison of services provided by the Colorado BI Waiver, the Kansas BI Waiver, and the New Mexico Centennial Care Community Benefit.

Service	Colorado BI Waiver	Kansas BI Waiver	New Mexico Centennial Care
Adult day services	Yes		Yes
Assistive devices	Yes	Yes	
Assisted living			Yes
Behavioral management	Yes		Yes
Attendant support	Yes		Yes
Community supports			Yes
Day treatment	Yes		
Enhanced Care services		Yes	Yes
Financial management		Yes	
Home delivered meals	Yes	Yes	

Home modification	Yes		Yes
Housing		Yes	
Medication Reminder	Yes	Yes	
Independent living skills training	Yes		
Mental health counseling	Yes		
Non-medical transport	Yes		
Peer mentorship	Yes		Yes
Personal care	Yes	Yes	Yes
Personal emergency response system	Yes	Yes	Yes
Rehabilitation therapies		Yes	Yes
Respite Care	Yes		Yes
Specialized medical equipment	Yes		Yes
Substance abuse counseling	Yes		
Supported living program	Yes		
Transition setup	Yes		
Transitional living program	Yes	Yes	Yes

Although the Centennial Care Community Benefit offers persons disabled by BI a track by which they can seek coverage for long-term support services, this program suffers from three significant drawbacks:

- 1) The services are not specific to the needs and deficits in BI, and often not appropriate or helpful;
- 2) The services are challenging to access for persons living with BI;
- 3) The services are underutilized by persons living with BI, and therefore not accomplishing their intended purpose.

The number of clients utilizing Centennial Care is likely far below the tens of thousands of New Mexicans estimated to be disabled by BI and illustrates the significant gap between a coverage pathway on paper, but that does not meet the needs of the citizens of New Mexico.

Additional obstacles that prevent persons living with BI from successfully applying for the Community Benefit include:

- 1) BI often results in significant cognitive, emotional, and behavioral deficits that impair one’s ability to complete complex tasks, such as obtaining and filling out necessary forms and applications;
- 2) The consequences of BI are immediate, whereas application and implementation of services takes a long period, resulting in significant loss of quality of life;
- 3) There are significant difficulties in accessing and comprehending the application materials;
- 4) There is a requirement to meet a Nursing Facility Level of Care, in which an individual requires assistance with two or more activities of daily living, which includes prompting and cueing of the ADLs;
- 5) Lack of oversight of the three MCOs by a state entity may contribute to variability in rates of application, acceptance, and maintenance of clients in the Community Benefit.

Recommendation: The State of New Mexico should recognize the limits of the Centennial Care Community Benefit and how it cannot address the specific needs of the brain injury population. A Brain Injury Waiver program would have a pathway for entry that is easy for persons with cognitive deficits to navigate; that assists persons in obtaining a formal diagnosis of brain injury; that ensures adequate acceptance rates to this program; and that oversees the utilization of this program.

Key Finding #8: A non-Medicaid brain injury program exists, the Brain Injury Services Fund, but only funds crisis interim services, whereas most disabled BI patients require long term community supports.

Rationale: The Brain Injury Services Fund Program, also known as the Brain Injury Program or BISF Program, is designed to provide statewide short-term services to New Mexicans living with Brain Injury (<https://www.hsd.state.nm.us/lookingforassistance/brain-injury/>). This includes those with Traumatic Brain Injury (TBI) or other Acquired Brain Injury, such as stroke, aneurysm, anoxia, brain tumor, brain infection, Shaken Baby Syndrome/Abusive Head Trauma, or exposure to chemical/toxic substances.

The Brain Injury Services Fund was created in 1997 and placed in a trust fund for use by persons who have sustained a traumatic brain injury. The Trust Fund Program provides unique services to persons with an approved BI diagnosis. The proposed regulations for the TBI Trust Fund ensures that services to individuals living with BI are clear, concise and accessible.

The Brain Injury Services Fund Program offers Service Coordination and Home and Community Based Services, including Professional Life Skills Coaching, to eligible residents of New Mexico. This program is designed to be a short-term program, which assists qualified individuals to achieve greater independence in addressing a crisis situation, for example, those who need assistance in applying for Medicaid or those who do not qualify for Medicaid and lack responsible payer sources for needed services.

Individuals are eligible for services through the BISF if they have been diagnosed with a BI, which has been confirmed by a licensed medical professional or psychologist. The BISF Program is funded, in part, from a \$5 fee that is added to all New Mexico traffic violation tickets. At this time, the BISF serves 121 participants on this program. However, funding of this program is not secured, as House Bill 139 eliminates the \$5 traffic ticket fees that funds the BISF, beginning in 2024.

The BISF Program also offers resource materials and training/educational opportunities specific to individuals with BI, family members, professionals, and other interested persons through the New Mexico Brain Injury Resource Center.

There are significant drawbacks to this program that limit its utility and helpfulness for people with BI. Most notably, it does not provide long-term services for program participants, and also has a \$4,000 annual budget, with a \$75,000 lifetime maximum budget. Whereas the above sections of this report clearly highlight the chronic nature of BI and the need that people with BIs have for ongoing supports.

Recommendation #8: The State of New Mexico should further fund and maintain the BISF as a crisis interim program. The State should further expand the program to be an entry point or bridge to long-term supports offered by a Brain Injury Waiver program for those who qualify.

Key Finding #9: Brain injury surveillance and registries are two means of obtaining data for appropriate resource provisioning, each with their own advantages and disadvantages.

Rationale: In public health, registry and surveillance are two distinct but related concepts that play important roles in monitoring and managing health-related data.

A registry is a systematic collection of data about individuals or cases that share a particular characteristic or diagnosis. These registries are typically established for specific diseases, conditions, or events. Registries are often used for tracking and monitoring purposes, such as cancer registries that collect information about cancer cases in a specific population. They can be disease-specific (e.g., TBI registry, cancer registry, diabetes registry) or event-specific (e.g., birth registry, trauma registry). Registries are usually more detailed and comprehensive, containing in-depth information about individual cases, including demographics, clinical characteristics, treatments, outcomes, and follow-up data.

An advantage of a BI registry is that it can assist persons with BI in accessing the system of care. A disadvantage is that it is typically voluntary, opt-in only, and thus cannot provide a clear “snapshot” of the impact of BI across the state.

Surveillance, on the other hand, is a broader term that refers to the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event. This event could be a disease, condition, or risk factor. Surveillance aims to provide timely information for action. It helps in the detection of outbreaks, understanding trends, and assessing the impact of public health interventions. Public health surveillance may involve the collection of aggregated data from multiple sources, including registries, hospitals, clinics, laboratories, and other health facilities. Surveillance data may be less detailed at the individual level compared to what is found in a registry. It is often focused on patterns, trends, and the distribution of health events in a population. Examples of surveillance programs include monitoring the prevalence of injuries, incidence of infectious diseases, tracking vaccination coverage, and studying the prevalence of risk factors like substance use.

The key difference registry and surveillance lies in the scope and depth of information collected. Both registries and surveillance are critical tools in public health that help inform policy decisions, guide interventions, and contribute to our understanding of health trends and outcomes in populations. They work hand-in-hand to support effective public health practice.

Recommendation: The State of New Mexico should prioritize establishing both a comprehensive system of brain injury surveillance, as well as a robust brain injury registry.

Key Finding #10: NM has a partial brain injury surveillance system, whereas it has no registry.

Rationale: The following information describes the current data sources, data collection systems, and various streams of information that the State of New Mexico obtains with regard to BI. At this time there is no single website, dashboard, or data repository where information about BI in New Mexico is collected, aggregated, and displayed so as to provide an up-to-date snapshot of its impact.

The New Mexico Indicator Based Information System ([NM-IBIS](#)) is a comprehensive online data system that provides access to a wide range of public health-related data for the state of New Mexico. NM-IBIS aggregates data from various sources to provide a comprehensive view of public health indicators. The system integrates data from multiple sectors, including public health and healthcare, and from state and federal agencies, as well as other relevant organizations. The data sources for NM-IBIS include vital records (e.g., death and birth data), morbidity data (e.g., Hospital Inpatient Discharge Data (HIDD), Emergency Department (ED) Data), health survey data (e.g., BRFSS, YRSS, PRAMS), and demographic data (e.g., American Community Survey).

Mortality Data

Death Data ([Bureau of Vital Records and Health Statistics](#)) - This comes in two forms, a general use database populated from death certificate information but without identifying information, and a more secure/limited access version with the identifying information. This data is regularly used to provide general estimates of mortality of New Mexico residents, determine leading causes of death, describe mortality by race, ethnicity, age, and geography. The death dataset is typically used for linkage projects to connect records of individuals across multiple datasets.

- [CDC Wonder](#) - This CDC run website that is populated from vital records information across the country. We use this often to generate comparison data for New Mexico vs United States or New Mexico vs other states.
- Violent Death Reporting System (VDRS - sometimes referred to as NMVDRS (New Mexico-VDRS) or NVDRS (National VDRS)) - This dataset takes deaths from violence related causes and collects additional information to better describe outcomes in this group. The VDRS data for New Mexico is held by the Office of Injury and Violence Prevention (OIVP) at the New Mexico Department of Health (NMDOH).
- Child Fatality Review Board (CFR) - This is a dataset created following interdisciplinary reviews of child deaths for suicide, child abuse and neglect, unintentional injuries, and other categories. The CFR program for New Mexico is housed within the OIVP at NMDOH.
- Office of Medical Investigator (OMI) - The New Mexico Office of Medical Investigator shares records with some DOH Epidemiologist. This data is very similar to death data and can be used for linkage projects or explorations of questions that are not well answered in death certificates.

Hospital/Emergency Services Data

- Emergency Department Data (ED) - This is a yearly dataset of emergency department visit information. This data is housed in the [health systems epidemiology program](#) at DOH.
- Hospitalization Inpatient Discharge Data (HIDD) - This is a yearly dataset of people who were admitted to an inpatient hospital setting. This is similar to ED, but some health conditions are better captured here. This data is also housed in the health systems epidemiology program.
- [National Syndromic Surveillance Program \(NSSP - but often referred to here as ESSENCE\)](#) – ESSENCE (Electronic Surveillance System for the Early Notification of Community-Based Epidemics) is a public

health surveillance system designed to provide early warning of potential public health threats. This is a more "real-time" data set of mostly emergency department visits across hospitals in the state. ESSENCE is hosted by the Centers for Disease Control and Prevention (CDC). ESSENCE collects and analyzes syndromic surveillance data from a variety of sources, including hospital emergency departments (ED), urgent care centers, and other healthcare facilities. Nearly 6000 health care facilities across the United States contribute ED data to ESSENCE. This data includes information on symptoms, diagnoses, and other health-related information. Although pivotal for early detection of health emergencies, the data has certain limitations. Notably, it does not cover all care facilities, potentially underestimating the number of injuries and other health-related conditions. The data is also preliminary and might vary due to factors like seasonal population changes. In addition, there are some issues around inaccuracies in classification of race/ethnicity.

- New Mexico EMS Tracking and Reporting System (NMEMSTARS or Biospatial) – This is a records of emergency medical services (ambulance but sometimes fire department also) visits in very close to real-time (accurate within 24 hours). Like ESSENCE, NMEMSTARS has some issues around inaccuracies in classification of race/ethnicity.

Survey Data

- Youth Risk and Resiliency Survey (YRRS or sometimes YRBS) - This is a survey administered in public schools of New Mexico middle school and high school students about a variety of health-related topics. NMDOH survey enough students to be able to produce district-level reporting, so New Mexico sample includes about 30,000 students every other year.
- Behavioral Risk Factor Surveillance System (BRFSS) - This is a telephone-based survey of New Mexico adults for health outcomes administered annually. The BRFSS aims to interview at least 6,000 adults a year. Each year the BRFSS accepts proposals for optional modules for the next survey administration.
- Pregnancy Risk Assessment and Monitoring System (PRAMS) – This is a survey of new mothers to improve maternal and infant health.

Increasing knowledge and awareness of BI, how to prevent it, and what to do when a person has sustained a BI, is one of the most important interventions that can be instituted with regard to a system of care in New Mexico. While the above data streams represent important efforts to comprehensively assess injury and disability in the State, their fragmented nature make them not well-suited to educating the public about BI. To that end, a central online portal by which a comprehensive BI epidemiology snapshot and system of care for New Mexicans is presented and accessed online would be of immense benefit to patients and families who are struggling to find information about BI.

Recommendation: The State of New Mexico should provide an online surveillance dashboard that is specific to brain injury, which provides a single source of regularly updated data on prevention, incidence, prevalence, and impact of brain injury in the state, and can serve as a resource for persons to connect with and obtain assistance and services.

Key Finding #11: A brain injury registry may be funded through a state-federal demonstration grant, such as those previously obtained by the State of New Mexico to establish other system components.

A BI registry, combined with an iterative needs assessment process, will allow prospective data to be gathered regarding the clinical, physical, and psychosocial functioning and disability of persons living with BI, and permit more accurate and targeted state interventions to be performed to improve their quality of life. While there may be hesitancy on the part of BI patients to register, given a concern for privacy, a publicity campaign can generate awareness and obtain buy-in.

Fourteen other states have some form of a BI or TBI registry. There is also a state TBI registry coalition seeking to establish a national registry (<https://nationaltbiregistry.org/resources/>). A New Mexico BI registry could be administered by several different entities, such as a state health-related agency (DOH, GCD, etc). It could also be administered by a BI advocacy organization (BIANM, etc) or a medical/academic partner. Other clinical populations are served by state registries, such as the special needs registry housed within Aging and Long-Term Services, and may serve as templates for initiating a BI registry. A number of federal programs exist to assist states in establishing BI-specific programs, which are outlined here. New Mexico has already taken advantage of several of these programs, but to date has never applied for funds to establish a BI registry.

Administration for Community Living (ACL) TBI State Partnership Grant Program: The federal government has provided financial assistance to states to set up TBI registries, through the Administration for Community Living (ACL) TBI State Partnership Grant Program. ACL's TBI Technical Assistance and Resource Center helps TBI State Partnership Program grantees promote access to integrated, coordinated services and supports for people living with TBI, their families, and their caregivers. The Center also provides a variety of resources to non-grantee states, people living with TBI, policymakers, and providers including "[Building Up TBI Systems: Tools for Successful TBI State Programs.](#)"

No Wrong Door Program: The ACL's No Wrong Door Program provides funding to States to set up an opt-in, integrated, state-wide, system to facilitate individuals with BI (and other disabilities and chronic illnesses) and their caregivers receiving Long Term Supports & Services while living in the community. This program enables an individual or a family to approach any registered organization in the state (including educational; healthcare; center for independent living; aging, disability, or BI; public housing; behavioral health; faith-based) and connect with the services and support they need, with expedited referrals resulting in efficient, speedy, comprehensive care. People living with BI need this, because cognitive deficits may result in people not realizing they need help and/or not knowing how to get help.

Medicaid Administrative Claiming (MAC): MAC funding enables state and community agencies to support the efficient administration of Medicaid by qualifying individuals for Medicaid and ensuring they receive the services they need so they do not deteriorate, thus keeping them out of the hospital. For example, a case manager at a community agency may assist a person with BI with safety, supports, and services while applying for and waiting for Medicaid approval. This funding has the potential to fill gaps in existing BI crisis care in NM. Eligible activities under MAC result in a 50% salary match.

National Association of State Head Injury Administrators (NASHIA): NASHIA offers resources, technical assistance, and access to consultation services for state governments and their partner organizations. NASHIA's team understands the specific needs of state governments and the nuances associated with building service delivery systems for individuals with BI and their families (<https://www.nashia.org/>).

Recommendation: The State of New Mexico should establish a brain injury registry to provide access to the state brain injury system of care. It should do so by identifying a state entity to apply for and administer funds from the federal government to improve the brain injury system of care; and by appointing a state

government representative to the National Association of State Head Injury Administrator to access resources for building sustainable systems of care that are comprehensive, culturally sensitive, person-centered, and inclusive of individuals with brain injury and family members.

Summary of Recommendations

Recommendation #1: A well-established, evidence-based system of care for brain injury should form the basis for recommendations regarding brain injury services.

Recommendation #2: The State of New Mexico should formally adopt an evidence-based brain injury system of care to increase access to services, reduce disability, improve the quality of life of its citizens, and reduce costs to the state.

Recommendation #3: The State of New Mexico should recognize brain injury as a public health issue as serious as opiate use and obtain accurate data about brain injury-related disability in New Mexicans.

Recommendation #4: The State of New Mexico should improve the components not well established in the current system of care for brain injury, through the following:

- 1) Train a brain injury informed workforce;
- 2) Establish a dedicated neurorehabilitation facility;
- 3) Support a Brain Injury ECHO program to improve access to specialists;
- 4) Provide services and supported housing specifically for persons living with brain injury;
- 5) Establish a clear, convenient access hub or brain injury system framework.

Recommendation #5: The State of New Mexico should defer seeking to change Medicare or commercial insurance coverage of brain injury care at this time.

Recommendation #6: The State of New Mexico should create and designate a Medicaid Brain Injury Waiver program, staffed by personnel who are trained and knowledgeable in brain injury, under which persons living with brain injury can qualify for and receive brain injury-specific long-term care.

Recommendation #7: The State of New Mexico should recognize the limits of the Centennial Care Community Benefit and how it cannot address the specific needs of the brain injury population. A Brain Injury Waiver program would have a pathway for entry that is easy for persons with cognitive deficits to navigate; that assists persons in obtaining a formal diagnosis of brain injury; that ensures adequate acceptance rates to this program; and that oversees the utilization of this program.

Recommendation #8: The State of New Mexico should further fund and maintain the BISF as a crisis interim program. The State should further expand the program to be an entry point or bridge to long-term supports offered by a Brain Injury Waiver program for those who qualify.

Recommendation #9: The State of New Mexico should prioritize establishing both a comprehensive system of brain injury surveillance, as well as a robust brain injury registry.

Recommendation #10: The State of New Mexico should provide an online surveillance dashboard that is specific to brain injury, which provides a single source of regularly updated data on prevention, incidence, prevalence, and impact of brain injury in the state, and can serve as a resource for persons to connect with and obtain assistance and services.

Recommendation #11: The State of New Mexico should establish a brain injury registry to provide access to the state brain injury system of care. It should do so by identifying a state entity to apply for and administer funds from the federal government to improve the brain injury system of care; and by appointing a state government representative to the National Association of State Head Injury Administrator to access resources for building sustainable systems of care that are comprehensive, culturally sensitive, person-centered, and inclusive of individuals with brain injury and family members.

Resources List

New Mexico

Brain Injury Alliance of New Mexico:

<https://www.braininjurynm.org/brain-injury-care-network/>.

New Mexico Brain Injury Service Fund program:

<https://www.hsd.state.nm.us/lookingforassistance/brain-injury/>

New Mexico Centennial Care overview:

<https://www.hsd.state.nm.us/lookingforassistance/centennial-care-overview/>

New Mexico Centennial Care Community Benefit program:

<https://www.hsd.state.nm.us/community-benefit-program/>

New Mexico Indicator Based Information System:

<https://ibis.doh.nm.gov/Alert.html>

New Mexico Department of Health, Bureau of Vital Records and Health Statistics:

<https://www.nmhealth.org/about/erd/bvrhs/>

Regional

Colorado Department of Health Care Policy and Financing Brain Injury Waiver program:

<https://hcpf.colorado.gov/brain-injury-waiver-bi>

Kansas Department for Aging and Disability Services Brain Injury Waiver program:

[https://kdads.ks.gov/kdads-commissions/long-term-services-supports/home-community-based-services-\(hcbs\)-programs/programs/traumatic-brain-injury](https://kdads.ks.gov/kdads-commissions/long-term-services-supports/home-community-based-services-(hcbs)-programs/programs/traumatic-brain-injury)

National

Centers for Disease Control and Prevention Traumatic Brain Injury and Concussion:

<https://www.cdc.gov/traumaticbraininjury/index.html>

Brain Injury Association of America:

<https://www.biausa.org/brain-injury/about-brain-injury/nbiic/what-is-the-difference-between-an-acquired-brain-injury-and-a-traumatic-brain-injury>

Centers for Medicare and Medicaid Services Essential Benefits Bulletin:

<https://www.cms.gov/CCIIO/Resources/Files/Downloads/eHB-faq-508.pdf>

National Association of State Head Injury Administrators:

<https://www.nashia.org/resources-list/col0j7vwe0nza4wmvddbvmxffa65n>

Administration for Community Living:

<https://acl.gov/programs/post-injury-support/traumatic-brain-injury-tbi>

State Demonstration Grants Request for Applications:

<https://www.grants.gov/web/grants/view-opportunity.html?oppId=346926>

National TBI Registry Coalition:

<https://nationaltbiregistry.org/resources/>

ESSENCE: National Syndromic Surveillance Program:

<https://www.cdc.gov/nssp/index.html>

CDC Wonder online database for public health reports:

<https://wonder.cdc.gov>

CDC WISQARS:

<https://www.cdc.gov/injury/wisqars/index.html>

International

Ontario Neurotrauma Foundation:

<https://www.braininjuryguidelines.org>

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