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Q1 Define the problem: [Outline the challenge(s) your recommendation will address. Insert links to reports where appropriate.]

Individuals with TBI lack access to accurate and timely diagnosis, community reintegration, supported living, and other supports:

1. TBI is a chronic, but relatively stable condition that can include both cognitive and or physical impairments that limit a person's ability to live independently and access their community fully.
2. People with TBI are not served under the State's Developmental Disabilities programming, nor the dementia/Alzheimer's programming.
3. People with TBI can be young adults who will need long term services and supports for many years.
4. Over the past 30 years, the size of the TBI population and the need for services has grown throughout California.
5. For people under the age of 45, TBI is the most common global cause of mortality and disability, affecting all countries and societies (Caro, 2010).
6. In the United States, TBI is eight times more common than the diseases of breast cancer, spinal cord injuries, AIDS and multiple sclerosis combined (Kolb & Whishaw, 2009).
7. According to the Centers for Disease Control (CDC), roughly 2% of the US population, or 1.7 million people, suffer a traumatic brain injury annually (Langlois, 2004). Every year across the United States 52,000 die of traumatic brain injury; 275,000 are hospitalized and over 1.3 million are treated and released from emergency rooms (Langlois, 2004).
8. Sometimes cognitive and behavioral impairments due to a TBI may be overlooked by physicians who tend to concentrate on the physical injuries (Flanagan, 2008). General practitioners in particular fail to identify neuro-cognitive impairments in 35 to 90 percent of their TBI patients (Caro, 2011).
9. TBI diagnosis is responsible for approximately \$76.5 billion US in annual direct, indirect medical and rehabilitation costs and loss of productivity in our country (CDC, 2013).
10. In the US alone, costs associated with caregiver support equate to \$18 billion annually (Caro, 2011).
11. Each survivor is left with an average lifetime cost of care and rehabilitation of \$7 million (CDC, 2011).
12. For military service members, TBI is a significant health issue. Of the 2.2 million veterans returning from the Iraqi and Afghani combat theaters, up to 22.8% sustained a mild TBI as a primary or secondary diagnosis. These military and veteran personnel often have more than one health condition. The most common overlapping health disorders are PTSD, substance use disorders, depression, and symp-toms attributed to mild TBI. Because of this high incidence rate, TBI has become a major focus of the Veterans' Administration health initiatives (Institutes of Medicine, 2013).
13. According to the US Department of Justice, more than 2 million Americans are incarcerated (DoJ, 2006), with roughly 25 – 87% of these inmates self-reporting a TBI (Morrell, 1998). The prisoners who have experienced a TBI are also more susceptible to mental health problems (depression or anxiety); substance abuse disorders (both alcohol and drugs); anger issues and suicidal tendencies (CDC, 2007).
14. Adult offenders who have a history of TBI tend to enter the prison system at a younger age and remain there longer than inmates who have not experienced a TBI (William, 2010). Inmates with TBI also have a higher risk of re-offending (Williams, 2010).
15. Women inmates convicted of a violent crime are more likely to have sustained a pre-crime TBI and some other form of abuse (CDC, 2007).
16. Homelessness has been found to be directly related to both head injury and prior imprisonment (Kushel, 2005).
17. The incidence of TBI is higher in Hispanic/Latino and African American populations than for their White counterparts, but the relationship between minority status, TBI and outcomes is not well known (Arango-Lasprilla, 2007). With the minority population of the US reaching 45% of the total population by 2050, it becomes increasingly important to understand how culture is perceived in order to have successful outcomes.
18. In 2014, falls were the leading cause of TBI. Falls accounted for almost half (48%) of all TBI-related emergency department visits. Falls disproportionately affect children and older adults: (Centers for Disease Control and Prevention (2019). Surveillance Report of Traumatic Brain Injury-related Emergency Department Visits, Hospitalizations, and Deaths—United States, 2014. Centers for Disease Control and Prevention, U.S. Department of Health and Human Services.
 - a. Almost half (49%) of TBI-related ED visits among children 0 to 17 years were caused by falls.
 - b. Four in five (81%) TBI-related ED visits in older adults aged 65 years and older were caused by falls
19. TBI is sometimes
 - a. Under-reported- Patients think it's not a big deal and it will go away.
 - b. Under-diaanosed (initiallv missed due to other catastrophic bodilv iniurv)

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- c. Misdiagnosed. Sometimes cognitive and behavioral impairments due to a TBI may be overlooked by physicians who tend to concentrate on the physical injuries (Flanagan, 2008). General practitioners in particular fail to identify neuro-cognitive impairments in 35 to 90 percent of their TBI patients (Caro, 2011).
20. TBI is a life-long condition with the potential for cognitive and physical impairments and associated disability. Current medical care models are focused on the initial treatment and rehabilitation of injury, but there is minimal long term support for patients and families dealing with life-long disability.
21. People living with TBI need access to both medical services and psychological support. TBI survivors are often living with cognitive and physical impairments and need help adjusting to life as a disabled person. This change in lifestyle can lead to significant anxiety, depression, or other mental health conditions.
22. Critical TBI specific services are not available through other programs and funding sources in a way that adequately meets the unique needs of individuals with TBI including current Medi-Cal waiver services.
23. Given the growing need and demand for services for people living with TBI and their families, it is critically important to stabilize TBI site funding and to begin expanding services to all Californians.
24. TBI is a chronic disability that affects how people live and age in their communities.
25. There is a high correlation of TBI among individuals who are experiencing homelessness.

Q2 Pick your Master Plan for Aging goal(s): [Check the goal(s) your recommendation aims to fulfill. View MPA Framework document for reference]

Goal 1: Services & Supports. We will live where we choose as we age and have the help we and our families need to do so.

Q3 Choose your MPA Framework objective: [Check the objective(s) your recommendation will accomplish. View MPA Framework document for reference.]

Objective 1.1: Californians will have access to the help we need to live in the homes and communities we choose as we age.

Objective 3.2: Californians will have access to quality, affordable, and person-centered health care through delivery systems that are age-friendly, dementia-friendly and disability-friendly.

Q4 Outline your recommendation: [In one to two sentences, sketch out your idea for the Master Plan for Aging.]

- 1) **STATEWIDE:** Develop a plan to make TBI services available throughout the state as outlined by SB 398 of 2018 (Chapter 402, Statutes of 2018) that extended the TBI Program authorization through 2024; and support the Department of Rehabilitation (DOR) leadership in alignment with their 3-year TBI Partnership Grant (June 2018-May 2021) from the federal Administration for Community Living (ACL) to establish a statewide TBI Registry, a TBI needs assessment, develop a State Plan for TBI services and supports, and identify a sustainable funding source for the TBI Advisory Board and ongoing TBI services.
- 2) **LOCAL SERVICE COORDINATION:** Leverage, enhance, and expand local-level TBI programs that provide Community Reintegration, Supported Living, and other TBI LTSS service.
- 3) **MEDI-CAL WAIVER:** Develop a TBI Medi-Cal waiver and/or make available multiple Medi-Cal waivers for this population.
- 4) **EARLY DIAGNOSIS AND CONNECTION TO SERVICES:** Improve early diagnosis of TBI and other brain injuries to improve access to treatment and community living supports.

California Brain Injury Programs should operate with the goal of supporting and empowering individuals with acquired or traumatic brain injury. As brain injury occurs on a spectrum, individualized services must be available to survivors in order to effectively meet their needs. Furthermore, in order to support survivors throughout the duration of their recovery, services along a continuum of care must be available. BI can cause permanent, lifelong effects so acute and post-acute services are imperative to cognitive, physical, social, and societal outcomes (Stocchetti & Zanier, 2016--<https://ccforum.biomedcentral.com/articles/10.1186/s13054-016-1318-1>). It is recommended that programs addressing brain injury are comprised of the following services:

Community Reintegration:

- Early detection of and attention to brain injury is key to successful community reintegration after a brain injury (Brazinova et al, 2015--<https://www.ncbi.nlm.nih.gov/pubmed/26179747>)
- Medical rehabilitation, including speech, occupational, and physical therapies, should be available to all brain injury survivors. Those who have experienced clinically “mild” brain injuries could still benefit from acute rehabilitation, and low-income, homeless, and uninsured BI survivors need access to rehabilitation services at little-to-no cost.
- “Rehabilitation services, matched to the needs of people with TBI, as well as community-based non-medical services, are required to optimise outcomes over the course of recovery.” (Khan, Baguley, & Cameron, 2003) <https://www.mja.com.au/journal/2003/178/6/4-rehabilitation-after-traumatic-brain-injury>
- BI survivors need access to post-acute, continued rehabilitation services to support community reintegration at the highest level of functioning possible.
- Underserved and at-risk populations (e.g., veterans, survivors of domestic abuse, people experiencing homelessness) may need a larger net of services that includes various service providers and may need an extended continuum of care.

Supported Living Services:

- While acute and post-acute rehabilitative services will support independent living goals, additional support should be provided.
- Home visits, case management, and caregiving services should be provided.
- In-home supportive services (available through Medi-Cal) should be available to brain injury survivors.

Vocational Supportive Services:

- BI survivors have significantly higher risk for unemployment (Brain Injury Association of America, 2005). Pre-employment and employment services that help BI survivors return to work post-injury are necessary to decrease rates of unemployment and homelessness for this population.
- Supportive employment services will also support job retention, thus improving long-term outcomes.
- Access to a vocational counselor is helpful so BI survivors can assess their career path post-injury

Information & Referral:

- Brain injury co-occurs with mental illness, substance abuse, homelessness, and other medical challenges, so additional services may be needed. Information & Referral Services should be available to help survivors navigate potential services.
- After a brain injury, support in many different areas can be needed. The availability of information & referral services can increase the ability of a survivor to get the help they need.

In addition to these pillars of service, California’s TBI Programs should have a specific focus on at-risk and underserved populations by providing low cost services. Provision of these services reduces the frequency of low-income and homeless populations’ misuse/overuse of traditional medical services, which decreases loss of revenue incurred when those who cannot afford to pay hospital fees overuse/misuse of ER and emergency medical services

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...and emergency medical services.

In sum, when considering brain injury from the lens of population health, TBI services:

- Redistribute the burden of care for underserved populations, alleviating overpopulated homeless and rescue service centers
- Prevent hospital and ED revenue loss from unpaid medical cost and/or loss of productivity
- Complete a continuum of medical care that begins upon hospital entry and ends post-hospital rehabilitation discharge
- Increase our local workforce through vocational supportive services, decreasing risk of TBI-induced homelessness
- Increase education and respite for TBI survivors' family members and caregivers
- o Decrease guilt and family dysfunction
- Relieve the financial impact on caregivers (who lose income or quit jobs to provide care) through rehabilitation services delivered outside the home and designed to maximize the TBI survivor's personal independence and enable a return-to-work whenever possible.
- Increase community awareness of TBI prevention and rehabilitation processes through professional education and information/referral services
- Increase the overall viability of our community at-large

Program standards:

California TBI Programs should provide the following services:

- community reintegration
- supported living
- vocational support
- information & referral

CA TBI Programs should use person-centered metrics, or individual measures of inputs or outcomes that can be used to measure the impact on people due to the recommendation.

Staff should have the opportunity to become Certified Brain Injury Specialists through the Brain Injury Association of America

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Q5 Identify and quantify your target population: [Describe which groups of Californians will be impacted by this recommendation, with numbers if available.]

Individuals of all ages, including seniors with Traumatic Brain Injury.

- 1.7 million Americans sustain a TBI annually
- 1.3-2.5 million TBI-related visits to the Emergency Department (ED) annually
- 5.3 million Americans live with TBI-induced disabilities
- An estimated 350,000 TBI survivors currently live in California
- Vulnerable Populations:
 - Homeless
 - o TBI survivors are at increased risk for homelessness
 - Veterans
 - o From 2000-2015, 333,169 service-persons have suffered a TBI
 - o TBI veterans are 9 times more likely than civilians to re-hospitalize and need more extensive community reintegration assistance.
 - Victims of Violence
 - o Assaults are the leading cause of TBI for 15-24 year olds

Q6 Share your recommendations for an age-friendly California: [Insert detailed bullet points describing your Master Plan for Aging ideas.]

Master Plan include the underserved community of individuals with TBI.

Q7 Provide any supporting evidence for your recommendation: [Add links or summaries of research evidence that support your unique vision.]

<https://www.dor.ca.gov/Home/Tbi>

<http://www.catbi.org/>

Q8 Give examples of local, state or national initiatives that can be used as an example of best practices: [Provide any available links and sources.] Local: State: National: Other:

Local Example: The seven existing TBI sites provide direct services in the following locations:

- FREED Independent Living Centers serving Butte, Shasta, Sutter, Nevada, and Yuba counties
- Mercy Outpatient Rehabilitation Center serving Sacramento, Placer, El Dorado, Yolo, and Solano counties
- Services for Brain Injury serving Santa Clara and San Mateo counties; Central Coast Center for Independent Living
- New Options serving Monterey, San Benito, and Santa Cruz counties
- Jodi House Brain Injury Support serving Santa Barbara, San Luis Obispo, and Ventura counties
- Independent Living Services of Southern California serving Los Angeles County
- St. Jude Brain Injury Network serving Orange County

State and Local Example: Department of Rehabilitation Traumatic Brain Injury Program and California TBI Advisory Committee

National Example: Administration for Community Living <https://acl.gov/programs/post-injury-support/traumatic-brain-injury-tbi>

Q9 Provide a roadmap to implementation: [Insert any actions state agencies, legislators, counties, local government, or philanthropy can take to move this recommendation forward. Some of the entities listed below may or may not be applicable to each recommendation.] State Agencies/Departments: [action to be taken by Governor or specific state agencies] State Legislature: [legislation needed to implement recommendation] Local Government: Federal Government: Private Sector: Community-Based Organizations: Philanthropy: Other:

- State Agencies/Departments: [action to be taken by governor or specific state agencies] California Health & Human Services, Department of Rehabilitation – expansion of TBI Program to statewide program with appropriate funding. Behavioral Health services do not currently cover individuals with TBI unless you can prove they had a mental health disability prior to injury.
- State Legislature: [legislation needed to implement recommendation] Expansion of the TBI Program Statewide and expansion of services to individuals with acquired brain injury

Q10 Identify person-centered metrics: [What are the individual measures of inputs or outcomes that can be used to predict your recommended action's impact on people.]

Services should be provided through the person-centered service delivery model to reduce hospital readmissions, homelessness, and improve quality of life as determined by the individual.

Q11 Measuring Success: [Describe specific metrics that could be used to empirically measure the effectiveness of your recommendation]

The following person-centered metrics should be used to track outcomes:

- Community Integration Questionnaire (CIQ): The CIQ is a measure of activities of daily living with three subsections measuring 1) Home Integration, 2) Social Integration, and 3) Productivity. The CIQ is used by the 7 existing TBI sites and is reported on a quarterly basis. This measure should be supplemented by a more subjective and comprehensive outcome measure.
 - o Barry Willer Ph.D., who was the principal investigator in developing the CIQ, holds the copyright. Permission for use of the CIQ is freely given but should be requested, by contacting him at the Centre for Research on Community Integration at the Ontario Brain Injury Association, 3550 Schmon Parkway, Thorold, Ont L2V 4Y6, Canada, email: bswiller@buffalo.edu
 - Quality of Life After Brain Injury Survey (QOLIBRI): The QOLIBRI Survey asks how satisfied or how bothered brain injury survivors are by various aspects of their lives post-injury. Its subsections include 1) Cognition, 2) Sense of Self, 3) Independence, 4) Social Relationships, 5) Emotions, and 6) Physical Problems.
 - o <https://qolibrinet.com/registration-for-use/>
- Surveys should be administered to brain injury survivors every six months, and CA TBI Programs should compile results to identify statewide trends and to evaluate outcomes.

Q12 Measuring Success: [How would we know that the implementation of your recommendation is successful?]

Short term: By 2020...

By 2021, develop a statewide strategic plan to expand TBI services statewide in collaboration with TBI Advisory Committee.

Mid term: By 2025...

identifying and accessing funding from multiple state-funded programs (e.g. Homeless, Mental Health, Health Care, Corrections, etc.) and continue the TBI advisory board to compensate for the end of ACL grant funding in May 2021.

Long term: by 2030...

All Californians living with a TBI have access to person-centered services for community reintegration, supported living, and employment.

Q13 Provide data sources: [What existing data can be used to measure success or progress?]: Existing data sources: [specify datasets, variables, and data owner/location] Suggestions for data collection to evaluate implementation of this goal when no data sources exist:

Testa, JA, Malec JF, Moessner AM, Brown AW. Predicting family functioning after TBI: Impact of neurobehavioral factors. *Journal of Head Trauma Rehabilitation*. 2006 May-June; 21(3):236-47.

Incidence of traumatic brain injury in the United States, 2003. Rutland-Brown W, Langlois JA, Thomas KE, Xi YL *Journal of Head Trauma Rehabilitation*. 2006 Nov-Dec; 21(6): 544-8.

Ibid.

Highley J.L. Traumatic brain injury among homeless persons: Etiology, prevalence and severity (B.J. Proffitt, Ed.). Nashville: Health Care for the Homeless Clinicians' Network, National Health Care for the Homeless Council, Inc., June 2008.

DoD Numbers for Traumatic Brain Injury, 2000-2015 Q1-Q2. U.S. Department of Defense; Defense and Veterans Brain Injury Center (DVBIC). August 2015.

Drag, Lauren PhD; Renninger, Christopher BS; King, Robert BS; Hoblyn, Jennifer MD, MPH. Predictors of Inpatient and Outpatient Healthcare Utilization in Veterans With Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation*. 2013 Jan-Feb; 28(1): 39–47.

Faul M, Xu L, Wald MM, Coronado VG. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010.

Finkelstein E, Corso P, Miller T. *the Incidence and Economic Burden of Injuries in the United States*. New York, NY, USA: Oxford University Press; 2006.

Traumatic Brain Injury in the United States 2001-2010. Centers for Disease Control and Prevention (CDC), National Center for Injury Prevention and Control, Division of Unintentional Injury Prevention. January 2015. Web.

http://www.cdc.gov/traumaticbraininjury/get_the_facts.html

Ibid.

Oxford Analytica. (August 25, 2006). United States: Plan to aid homeless may save billions. Web. <http://www.oxan.com/display.aspx?ItemID=DB128559>.

Q14 Identify potential costs and/or savings: [Provide any research, actuarial analysis or other evidence of the cost of, or potential savings from, implementing your recommendation.]

Financial Impact on Medicine

- Direct and indirect costs of TBI to hospitals and ED's (includes medical cost and loss of productivity) estimated at \$60 billion in the U.S. annually
- TBI-related ED visits increased by 70% from 2001-2010
- TBI-related hospital visits increased by 11% from 2001-2010
- Of the \$10.95 billion spent on homeless care annually, 90% is medical

Q15 Prioritize your recommendation: [How would you prioritize your recommendation relative to other needs/priorities?] **High**

Q16 Contact information: [Let's stay in touch!]

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