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**National Association of State Head Injury Administrators**

***State Systems and Resources for People  
Living With Traumatic Brain Injury***

**National Information and Referral Support Center**

Rebeccah Wolfkief  
Executive Director

**Presenter from  
National Association of State Head Injury**



**Rebecca Wolfkiel, M.P.P.  
Executive Director  
NASHIA**

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**NASHIA is a nonprofit organization created to assist State government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families.**

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# Definition of Brain Injury

**Insult to the Brain:  
Occurs After Birth  
Not Hereditary**

## Non-Traumatic or Acquired Brain Injury (ABI)

Brain damage that occurs after birth and is not caused by external force to the head. ABIs may be caused by disease or oxygen deprivation.

## Traumatic Brain Injury (TBI)

A disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head, or penetrating head injury.

Everyone is at risk for a TBI, especially children and older adults.

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# Impacts of a Brain Injury

Effects may include impairments related to:

- ▶ Cognitive processing, functionality and memory
- ▶ Movement
- ▶ Senses (e.g., vision or hearing)
- ▶ Emotional and behavioral functioning (e.g., personality changes, depression, unhealthy substance use)

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# Leading Causes of TBI

Falls	52%
Motor Vehicle Accidents	20%
Being Struck By/Against an Object	17%

Falls are the leading cause of TBI, disproportionately impacting children 0-17 years and older adults 65 + years.

81% of TBI-related ED visits for adults 65+

48% of TBI-related ED visits for children 0-17

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# Common Causes of TBI

## Non Traumatic Causes

Infection (Meningitis, HIV)

Neoplastic (tumor, cancer)

Vascular (stroke, aneurysm)

Metabolic (anoxia, hypoxia)

Neurotoxic (lead poisoning)

Demyelinating/Dementing – (MS,  
Parkinsons)

## Traumatic

Falls

Sports/Recreation.

Assaults

Homicide/Suicide Attempts

Intimate Partner Violence

Abuse (Elder, Child, Shaken Baby)

Motor Vehicle

Work/Industrial

Military Combat

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# National Epidemic

The CDC estimates that **5.3 million** U.S. citizens (**2 percent of the population**) are **living** with disability as a result of a **traumatic brain injury**.

Each year there are over 2.8 million TBI-related emergency room visits, hospitalizations and death in the United States. Over 837,000 of these incidents are among children.

Almost 155 people in the United States die each day from injuries related to a TBI.

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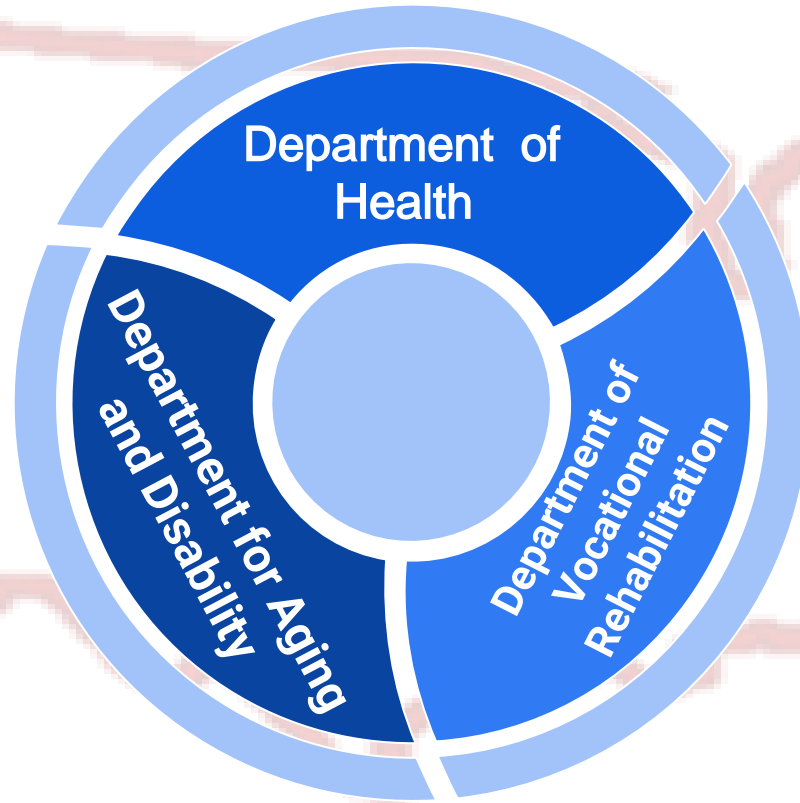
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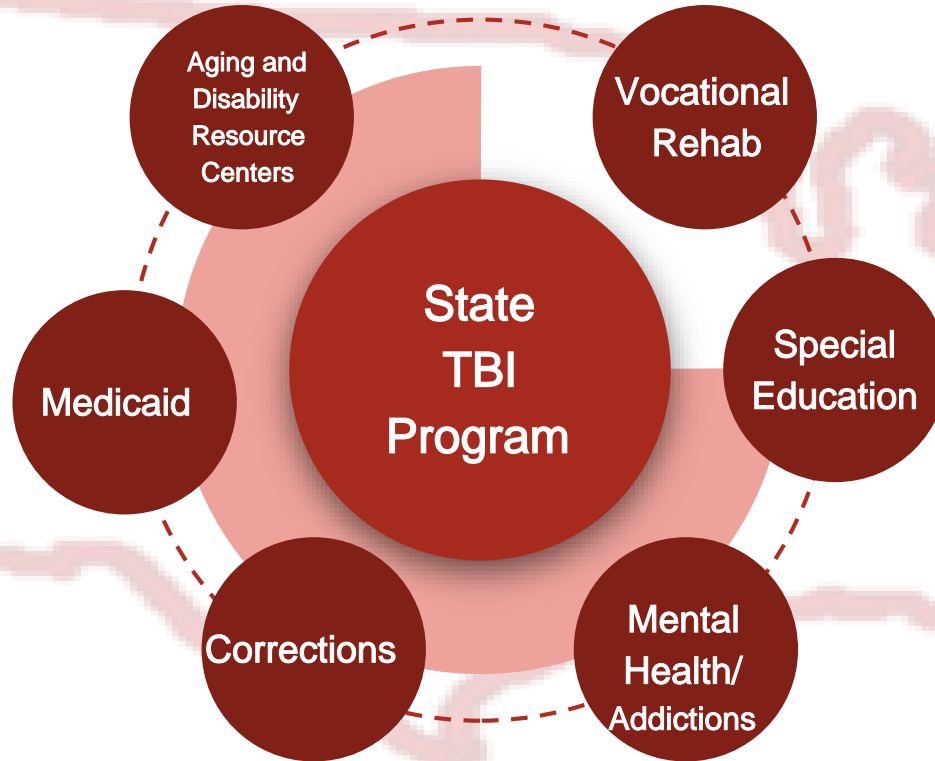
# State TBI Programs



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# State Agency Partnerships



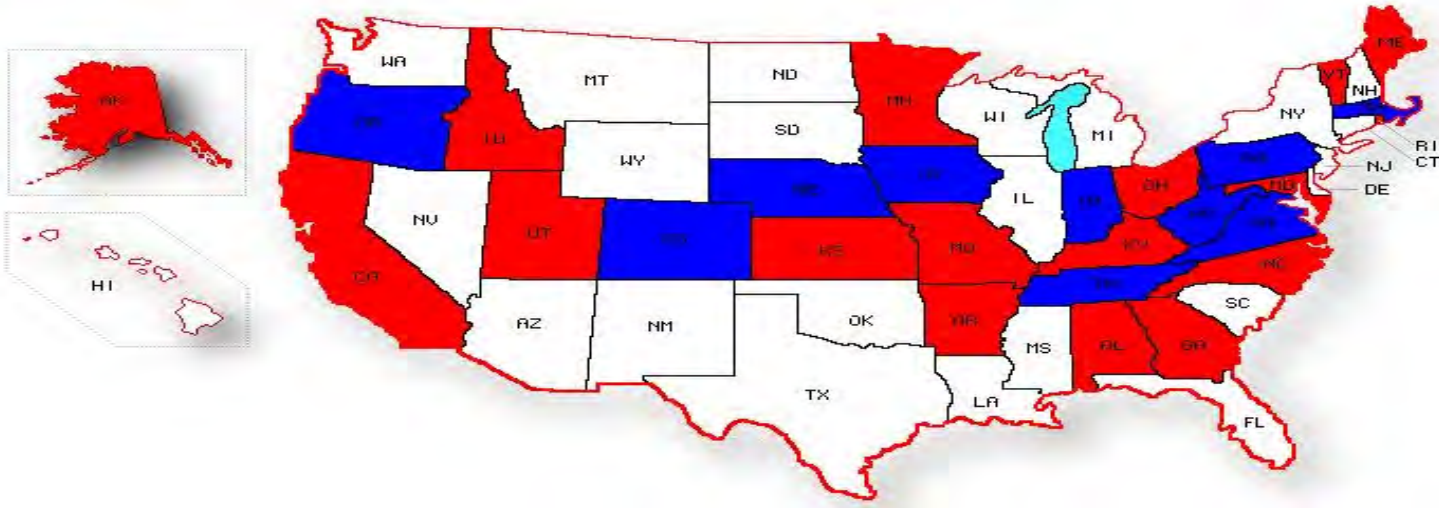
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# ACL TBI State Grant Program

## ACL grantees

- - Mentor States
- - Partner States



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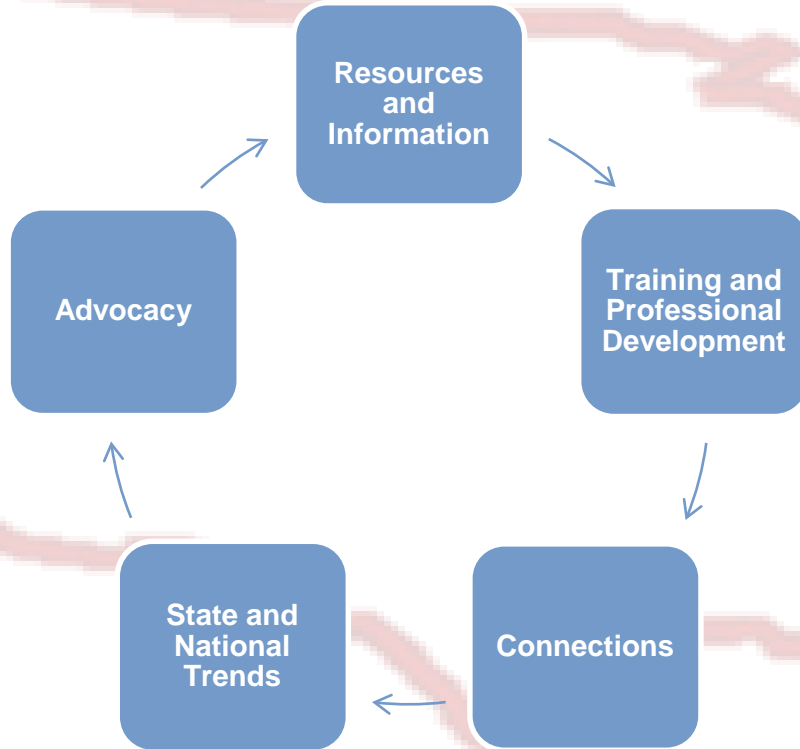
# ACL TBI State Grant Program

 <p>advisory boards &amp; survivor engagement</p> <p>MENTORS: Tennessee • West Virginia (Virginia) PARTNERS: Arkansas • Georgia • Kentucky • Maryland • Minnesota • Rhode Island, Alaska • California</p>	 <p>using data to connect people to services</p> <p>MENTORS: Indiana • Nebraska • Virginia PARTNERS: Alaska • Georgia • Idaho • Kansas • Minnesota • Missouri • Rhode Island • Utah • Vermont • California • Maine • Alabama</p>	 <p>return to learn &amp; return to play</p> <p>MENTORS: Pennsylvania • Oregon PARTNERS: Missouri • Utah</p>	 <p>criminal &amp; juvenile justice</p> <p>MENTORS: Colorado • Pennsylvania • Indiana PARTNERS: California • Vermont</p>	 <p>opioid use and mental health concerns</p> <p>MENTORS: Massachusetts • Virginia (West Virginia) PARTNERS: Kentucky • Maryland • North Carolina • Maine • Alabama • Ohio</p>
 <p>sustainable partnerships</p> <p>MENTORS: Iowa • Massachusetts • Tennessee PARTNERS: Georgia • Kansas • Kentucky • Maryland • Rhode Island</p>	 <p>transition and employment</p> <p>MENTORS: Indiana • Nebraska PARTNERS: • North Carolina • Vermont</p>	 <p>underserved populations</p> <p>MENTORS: Oregon • West Virginia PARTNERS: Arkansas • California • Idaho • Minnesota • Missouri • Utah</p>	 <p>waivers and trust funds</p> <p>MENTORS: Colorado • Iowa PARTNERS: • Arkansas • Idaho • Kansas • North Carolina • Ohio</p>	

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# NASHIA Provides



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# Maryland's Experience Enhancing ADRC through Brain Injury Partnerships



**Stefani O'Dea, MA**

Director, Office of Older Adults and Long Term  
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**Maryland Behavioral Health Administration**

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# How did it Begin?

## Long Term Care Rebalancing

Maryland participated in both the *Money Follows the Person Project (MFP)* and the *Balancing Incentives Project (BIP)*, which were aimed toward rebalancing long term care systems by enhancing community based long term services and supports and reducing reliance on institutional services such as nursing facility

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# Rebalancing: Single Entry Point / No Wrong Door

Maryland's rebalancing initiatives included enhancement of home and community based service waivers (1915c), implementation of community first choice (1915k), provision of transitional services for individuals transitioning from nursing facilities and other long term care facilities to community, and the development of a no wrong door/single point of entry system called Maryland Access Point.

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# Single Entry Point / No Wrong Door Maryland Access Point

## Historical Background

Maryland was one of 12 states that received grants to develop aging and disability resource centers in 2003. Federal rebalancing initiatives helped to expand these ADRCs into a statewide system with formal and informal partnerships in place with multiple State agencies, Centers for Independent Living, local behavioral health authorities and the Brain Injury Association of MD (BIAMD).

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# MARYLAND ACCESS POINT

YOUR LINK TO HEALTH & SUPPORT SERVICES

Maryland Access Point (MAP) is the Aging and Disability Resource Program in Maryland, designed to assist individuals with long term care needs and their caregivers to identify and locate services in their community. MAP is a centralized, single point of entry for access to the services provided by state agencies as well as other private, public and community based resources. [www.marylandaccesspoint.info](http://www.marylandaccesspoint.info)

Maryland Access Point provides free Options Counseling to help individuals and their caregivers develop long term care plans. Contact your local office to make an appointment <https://marylandaccesspoint.info/consumer/connect.php>.

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# Maryland's Lead Agency on Brain Injury

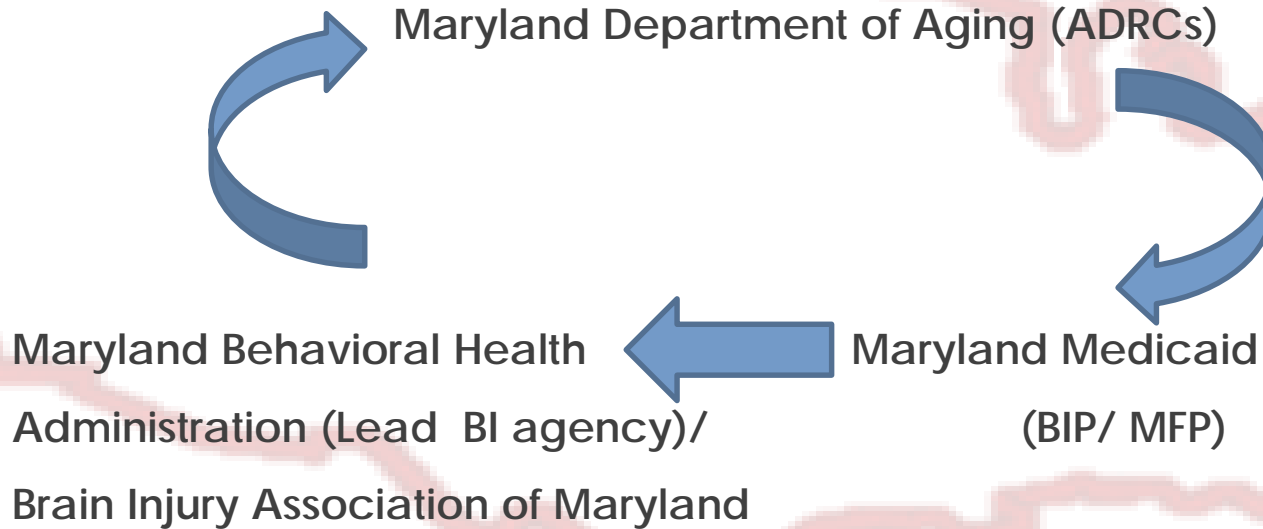
- ▶ Lead Agency= Behavioral Health Administration (BHA)
- ▶ BHA administers a 1915c waiver for adults with brain injury
- ▶ Lead agency staff participated in Maryland Long Term Care Rebalancing stakeholder meetings which lead to opportunities for partnering with the Medicaid Agency and the Maryland Department of Aging around No wrong Door design.
- ▶ Lead agency contracts with the Brain Injury Association of Maryland (BIAMD) to provide information and assistance about brain injury resources and program application assistance and case management to individuals in need of brain injury waiver services. [www.biamd.org](http://www.biamd.org)

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# Partnership = Progress



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# Acknowledgements

## Acknowledgements to:

- ▶ **Carrie Frazier, Liz Woodward, Maryland Department of Aging**
- ▶ **Anastasia Edmonston, Lead Agency TBI Project Coordinator/  
Statewide trainer**
- ▶ **Bryan Pugh, Caitlin Starr and Jessica Nesbit, Brain Injury  
Association of Maryland**
- ▶ **Rebecca Raggio, Maryland Medicaid/ MFP**

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# Maryland Brain Injury Partnership with Maryland Access Point

- ▶ **PRIMARY BRAIN INJURY RESOURCE FOR MARYLAND ACCESS POINT IDENTIFIED:** The Brain Injury Association of Maryland, BIAMD, was identified as the primary Brain injury resource for Maryland Access Point. BIAMD and lead agency also assisted with identifying other brain injury listings for the website.
- ▶ **MAP WEBSITE:** BIAMD listing provided with any brain injury related key word search of Maryland Access Point Website

# Maryland Brain Injury Partnership with Maryland Access Point

## ▶ TRAINING AND EDUCATION

- ◆ Lead agency and BIAMD conducts training for ADRC/ MAP staff during brown bag lunch webinars as well as in person training on topics related to brain injury and aging, person centered thinking, and Mental Health First Aid
- ◆ Lead agency sponsorship of BIAMD annual conference includes a resource table exhibiting MAP resources as well as scholarship program for MAP/ ADRC staff to attend the conference for free

# Maryland Brain Injury Partnership with Maryland Access Point

## ► **BRAIN INJURY SCREENING:**

- ◆ ADRC/ MAP intake staff complete the interRAI phone screen with callers inquiring about LTSS- Brain Injury screening question added to phone screen (SUD and MH questions also added)
- ◆ Positive screen leads to referral to BIAM for specific BI resources (MAP manual)
- ◆ Data available on number of individuals with BI accessing ADRC for assistance. 2017 data = 10% (of those administered level I screen)

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# Lessons Learned in Maryland

**Website Listings- Not all brain injury resources can be listed.**

- ▶ **Some individuals that experience a brain injury mainly need a clinician or physician with certain expertise (e.g. psychiatrists, psychologists, neuropsychologists, neurologists, neuropsychiatrists, neuro-ophthamologists, therapist)**
- ▶ **Some individuals living with a disability as a result of a brain injury may need long term services and supports, info about applying for Social Security, Medicaid or Medicare, housing resources, transportation resources and other resources that many individuals living with disabilities need.**
- ▶ **States may or may not have specialized HCBS waivers for individuals with brain injury- approx. ½ of states have Brain Injury Waivers and/ or Trust Fund programs**

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# Website Listings (continued)

- ▶ Most states have a lead agency on Brain Injury and most states have a non-profit advocacy and information organization (usually a brain injury association or a brain injury alliance affiliate) so linking to these entities allows callers to have a conversation about their needs with someone who has professional or sometimes personal experience with brain injury is crucial so make sure the lead agency and the state's brain injury affiliate is listed

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# Lessons Learned in Maryland

## Training core components:

- ▶ Understanding brain injury (brain injury 101)
- ▶ Recognizing that a caller may be living with (undisclosed or unidentified) brain injury
- ▶ Maximizing person centered approaches
- ▶ Understanding brain injury resources
- ▶ Aging with Brain Injury/ Risk of Brain Injury as we age (falls)
- ▶ Strategies for communicating with a person with a brain injury related disability
- ▶ Brain Injury and Co-occurring behavioral health conditions

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# Lessons Learned in Maryland

## Screening

- ◆ Asking a caller if he or she, or the person he or she is calling about, has had a brain injury is NOT best practice for screening.
- ◆ Identifying whether an individual has a history of brain injury is best done through series of conversational questions and knowing what to listen for. Maryland encourages use of the OSU TBI Identification Method <https://wexnermedical.osu.edu/neurological-institute/departments-and-centers/research-centers/ohio-valley-center-for-brain-injury-prevention-and-rehabilitation/osu-tbi-id>
- ◆ Information and Referral Specialists are not always able to conduct a full Screening, nor is a full screening warranted in all cases.

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# Brain Injury Partnerships & Evolution of I&R in Massachusetts



## Gabriela Lawrence-Soto

ACL Grant – Project Manager

**Massachusetts Rehabilitation Commission**

Community Based Services Department

**Statewide Head Injury Program**

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# Massachusetts Rehabilitation Commission (MRC)

- ▶ To provide comprehensive services to people with disabilities that will maximize their quality of life and economic self-sufficiency in the community.
- ▶ Accomplished through multiple programs within three service delivery areas:
  - ✦ Employment Services (Vocational Rehabilitation)
  - ✦ Disability Determination Services
  - ✦ **Community Living Services**
    - ✓ Community Based Services
    - ✓ Independent Living & Assistive Technology
    - ✓ Transition Services
    - ✓ Home Care Assistance Program
    - ✓ Protective Services
    - ✓ Community Housing

# Brain Injury System in Massachusetts



[www.mass.gov/mrc](http://www.mass.gov/mrc)



[www.biama.org](http://www.biama.org)

- 1985 established the Statewide Head Injury Program
- Traumatic Brain Injury Waiver in 2008
- Acquired Brain Injury Waivers in 2010
- Moving Forward Plan Waivers in 2013

# Statewide Head Injury Program

- ▶ Established in 1985
- ▶ Supports individuals living with a traumatic brain injury and their families to access services
- ▶ Serves residents of ALL AGES
- ▶ Funds for SHIP services come from:
  - State Appropriation
  - Trust Fund
    - DUI Surcharge
    - Speeding Ticket Surcharge
  - Traumatic Brain Injury Waiver
    - Provides supplemental funding for 100 individuals within SHIP who meet clinical and financial eligibility requirements, and who are at risk of institutionalization without funding



# SHIP: Brain Injury Services

## Offered

- Skills Training
- Residential Services
- Shared Living
- Adult Companion
- Regional Service Centers
- Worcester Community Center
- Social/Recreation Programs
- Respite Services
- Family Assistance Program
- Substance Use Services
- Technical Assistance regarding TBI

## Most Utilized Services

Of the 910 People actively receiving services:

- 59% - Case Management/ Coordination
- 10 % - Day Services
- 10% - 24-hour Residential and Supported Living Programs

# Medicaid Waivers in Massachusetts

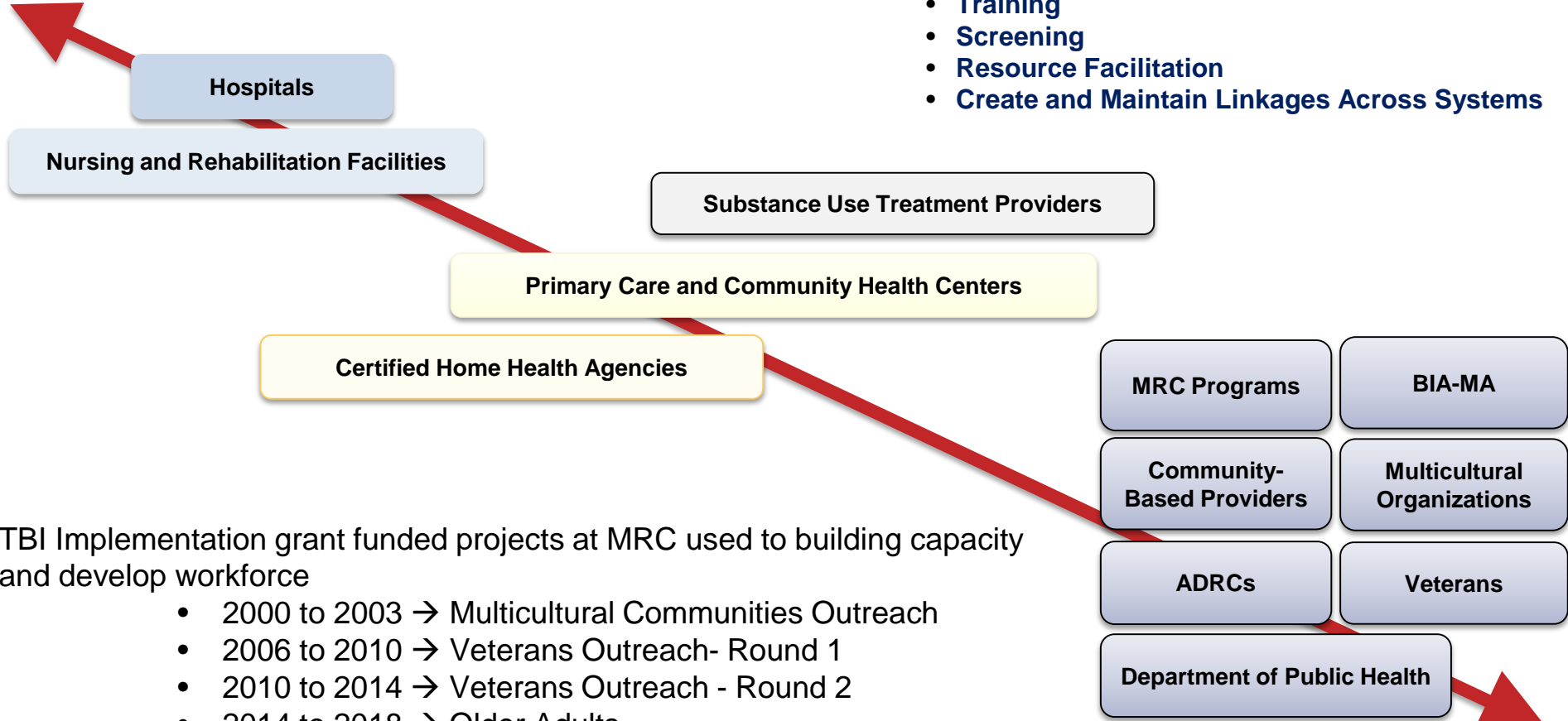
Massachusetts has a total of 9 MassHealth (Medicaid) waivers:

- ◆ 1 operated by the Executive Office of Elder Affairs
  - Frail Elder Waiver
- ◆ **3 operated by Massachusetts Rehabilitation Commission**
  - Traumatic Brain Injury (TBI) Waiver
  - Acquired Brain Injury Non-Residential Habilitation (ABI-N)
  - Moving Forward Plan Community Living (MFP-CL)
- ◆ 5 operated by Department of Developmental Services
  - Moving Forward Plan Residential Services (MFP-RS)
  - Acquired Brain Injury Residential Habilitation (ABI-RH)
  - HCBS - Adult Supports Waiver
  - HCBS - Community Living Waiver
  - HCBS - Intense Supports Waiver

# FACILITIES

# Capacity Building

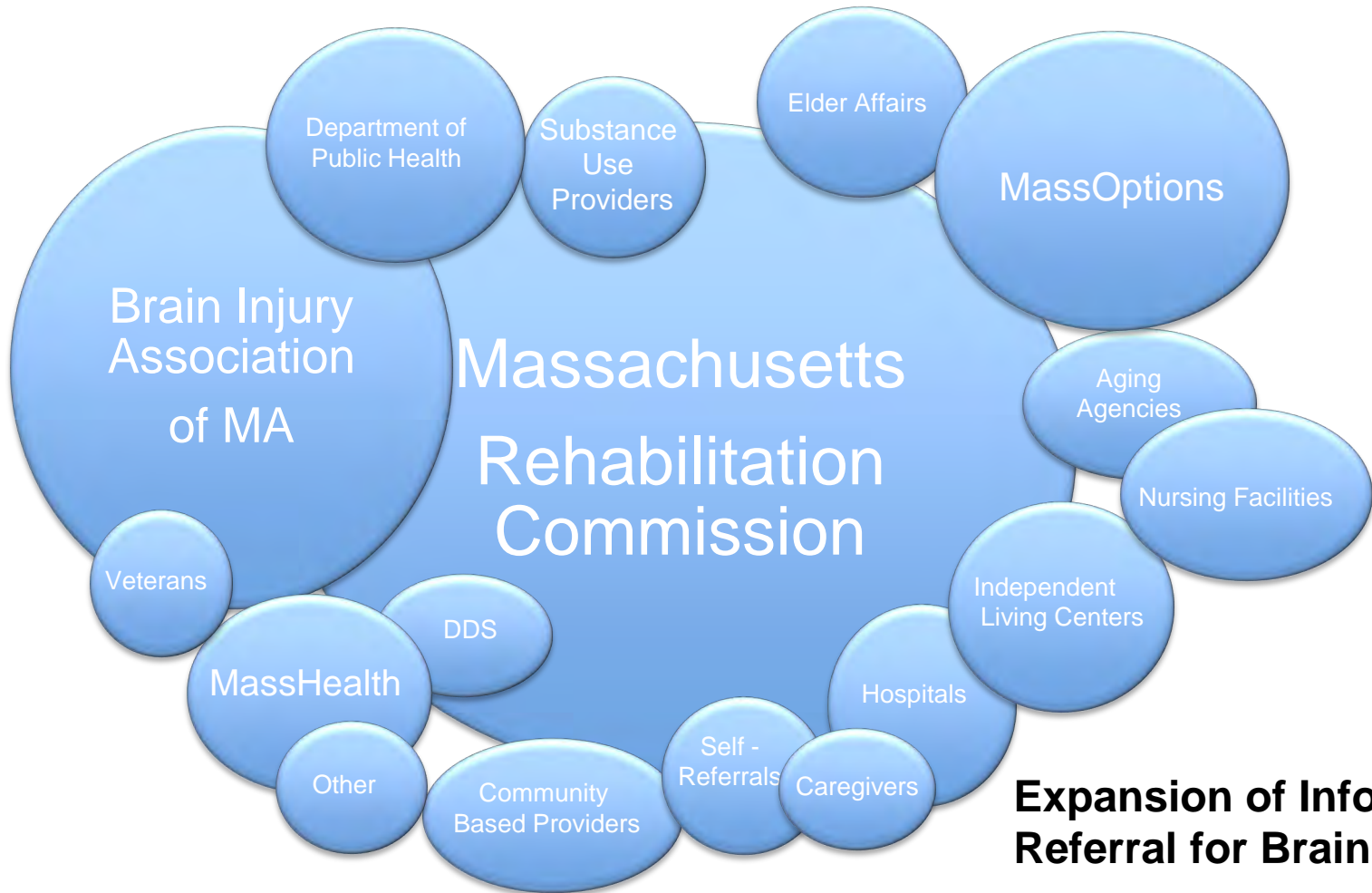
- Training
- Screening
- Resource Facilitation
- Create and Maintain Linkages Across Systems



TBI Implementation grant funded projects at MRC used to building capacity and develop workforce

- 2000 to 2003 → Multicultural Communities Outreach
- 2006 to 2010 → Veterans Outreach- Round 1
- 2010 to 2014 → Veterans Outreach - Round 2
- 2014 to 2018 → Older Adults
- 2018 to 2021 → Co-Occurring Substance Use

# COMMUNITY

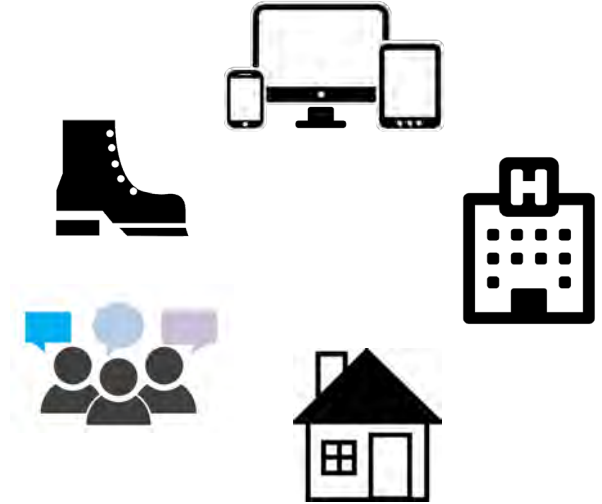


**Expansion of Information and Referral for Brain Injury in MA**

# Examples: I&R Touch Points in MA

## @ MRC

- ◆ ACL Grant Project Manager and Admin Staff
- ◆ SHIP – Regional Coordinators
- ◆ Ongoing education to other MRC Program staff
- ◆ Waiver Case Manager outreach to Nursing Facilities



## @ BIA-MA

- ◆ Information and Resource Specialists
- ◆ Outreach and Training efforts
- ◆ Support groups offerings

## @ The Aging and Disability Consortia's

- ◆ Ongoing in-services and relationship with Option Counselors
- ◆ Cross training of Case Managers and Intake Specialists at ASAPs and Transition coaches/coordinators, Long term services and supports staff, and ILC skills trainers in the ILCs
- ◆ MassOptions website (EOEA) - [www.massoptions.org](http://www.massoptions.org)

INTRODUCING...

# MASS OPTIONS

Your link to community services



TOLL-FREE **1-844-422-6277** OR VISIT **MassOptions.org**

Connections to services for elders and individuals with disabilities - simplified.

Right here when you don't know where to turn.

Massachusetts Executive Office of Health and Human Services

MassOptions Can Help!

# FAQs

FREQUENTLY ASKED QUESTIONS

## Need Help?

Call Toll Free:  
[844-422-6277](tel:844-422-6277)

Or

[Contact a Local ADRC](#)

[Chat Online](#)

[Email Us](#)

## The MassOptions Network



**We partner with a strong statewide network, including the Aging and Disability Resource Consortia (ADRC) and state agencies that provide services and supports.**

**Together, we work with you to find and choose the services and supports that best fit your needs.**

Explore this section to learn more about our network partners and agencies in your local community. Learn more about what they do and obtain contact information. MassOptions through our experienced network is your link to information about the many services and supports available.

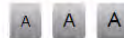
For more information about services and supports go to the [Finding Services and Supports](#) section.

**MassOptions we're here to help!**





Your link to community services



Advanced Search



About MassOptions

The MassOptions Network

Finding Services & Supports

Other Resources

Contact Us

[MassOptions](#) > Find Services and Supports

## Finding Services and Supports



Explore the many services and supports available for elders, people with disabilities, caregivers and family members.

## Access to Health Insurance and Benefits



MassHealth



Medicare



Other Insurance

## Community Services & Supports



Care Management



Caregiver Supports



Community Life



Coordinated Care Programs



Day Services



Equipment and Supplies



Financial Assistance



Emergency Services



Food and Nutrition



# Become Brain Injury Informed

## ▶ Activities you can do

- ◆ **Site visit – Invite or attend meeting with your local brain injury agency**
  - ▶ Foster partnerships
  - ▶ Exchange update contact information, specially after turn-overs
- ◆ **Collaborate in cross training efforts**
  - ▶ Attend or coordinate Health/Resources Fairs/ Meet and greets
  - ▶ Recruit or attend Conferences (such as an Attendee, Exhibitor, or presenter capacity)
  - ▶ Take advantage of educational webinars offered by NASHIA and your local Brain injury agency
- ◆ **Request and/or disseminate educational materials/info graphics beneficial to the population served**
- ◆ **ALWAYS Accommodate Symptoms of Traumatic Brain Injury**

# Recognizing that a caller may be living with (undisclosed or unidentified) brain injury

## REFRESHER!

### Effects of Brain Injury may include impairments related to:

- Cognitive Processing, Functionality and Memory
- Movement
- Senses (e.g., vision or hearing)
- Emotional and Behavioral functioning (e.g., personality changes, depression, unhealthy substance use).

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# What to listen for...

Tips that someone is having difficulty with LANGUAGE (receptive and/or expressive aphasia)

- ◆ Long pauses in conversation
- ◆ Word finding issues
- ◆ Poorly organized verbal responses
- ◆ Not able to answer questions directly

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# What to listen for...

## Tips that MEMORY is an issue:

- ▶ Unable to generate responses to questions, especially historical demographic information
- ▶ Seem to forget the question asked before they finish their response
- ▶ Ask the caller to repeat themselves, sometimes more than once
- ▶ Difficulty reporting on medications taken, doctors/health care providers information
- ▶ Need to pull someone into the conversation in order to provide information to the caller (this is to be encouraged)

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# What to listen for...

Tips that EMOTIONAL REGULATION/DEPRESSION/ANXIETY are an issue

- ▶ Emotional response to question is out of proportion to the question asked (get angry/sad when asked a seemingly innocuous question)
- ▶ Anger
- ▶ Weeping
- ▶ report isolation/estrangement from family and supporters

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# What to listen for...

Tips that there may be some PHYSICAL SEQUELA from a possible brain injury

- ▶ speech is very labored
- ▶ speaker sounds like they are intoxicated when you are pretty sure they are not
- ▶ Speaker reports utilization of adaptive equipment and or need for physical accessibility
- ▶ Speaker reports they are isolated-do not seek out community activities/supports

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# What to listen for...

## Other tips:

- ▶ Unemployed at age when employment peaks (45 year old hasn't worked in many years) and/or report getting but not keeping jobs
- ▶ Alcohol or drug use is disclosed
- ▶ Chronic pain such as headaches, orthopedic issues
- ▶ Taking multiple medications despite a relatively young age

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# So you think there is a brain injury, now what?

- **Ask the caller if he/ she may have had a serious injury that resulted in loss of consciousness.**
- **Report and document reasons for suspecting a brain injury in the consumer file within your agency.**
- **Adjust service plan/goals when appropriate.**
- **Follow up with summary of call via email or letter**
- **Refer caller to Lead agency or Brain Injury Association or Alliance or other available services in your state**

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**Thank you**

**Questions?**

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