



# New Jersey Advisory Council on Traumatic Brain Injury

April 15, 2025

### **Agenda**



Welcome, Introductions, Review of Minutes, Division Updates: 10:00am-10:05am

Jacqueline Moskowitz, Interim Executive Director, DDS

Brain Injury Alliance of NJ: 10:05am-10:10am

Barbara Chabner, Director of Education & Outreach

TBI Fund Updates: 10:15am-10:20am

Margaret Lumia, PhD, MPD

**Survivor Board Future Directions Presentation** 

**TBI and Aging:** 

Cathy Trapini 10:20am-10:50am

10:50am-11:00am

State Action Plan Development and Discussion: 11:00am-11:45am

Kelly Miller, Senior Manager for Technical Assistance, NASHIA

Open Discussion: 11:45am-12:00pm







### Welcome, Review of Minutes, Division Updates

Jacqueline Moskowitz, Interim Executive Director Division of Disability Services





# Brian Injury Alliance of New Jersey Update (October-December 2024)

Barbara Chabner
Director of Education and Outreach



### Workshops

- In-person and virtual workshops
- 133 workshops; 4,160 attendees
- Bilingual 9
- Wide range of topics including:
  - Brain Injury and Mental Health
  - Brain Injury and Domestic Violence
  - Brain Injury and Substance Use
  - Concussion
  - Head's Up, Seniors
  - Safety Presentations



### Workshops-ACL Counties

- Atlantic
- Camden
- Cape May
- Essex
- Mercer



### Community Event Exhibiting

- Community Fairs/Wellness Events
- 9 events attended
- Bilingual 4
- Exhibiting- ACL Counties
  - Atlantic
  - Mercer



### Coalition/Networking Meetings

- Community Coalition Meetings
  - Coalition meetings
  - Individual networking meetings
  - 80 attended
- Coalition/Networking-ACL Counties
  - Atlantic
  - Camden
  - Essex
  - Mercer



### Professional Conference Exhibiting

- Professional Conferences-5 statewide
  - School Health and Law
  - NAMI (National Alliance on Mental Illness)
  - NJAPHERD (Association for Health, Physical Education, Recreation and Dance)
  - NJSHA (Speech Language Hearing Association)
  - NJSSNA (School Nurse Association)



### Webinars and Facebook Live

- Hosted 3 webinars
  - Cultivating Mental Health After Brain Injury: Strategies for Emotional Well-Being and Recovery
  - Brain Injury Caregiving
  - Navigating Dating and Relationships After Brain Injury
  - 229 attended
- 2 Facebook Live Discussion
  - Discussed upcoming BIANJ Family Camp and Camp TREK
  - Conducted Facebook Live at art workshop for Brain Injury Journey: Exploring Resilience Through Art project



### Video Resource Hub

- Series of brief videos related to life after brain injury
- Topics include:
  - Disability Benefits
  - Social isolation
  - Working after brain injury
  - Transportation resources
  - Memory challenges
  - Organizational tips
- Translate into Spanish
- Updating written resources on some of same topics



### TBI Fund

- TBI Fund promoted at presentations/events
- 101 referrals to TBI Fund







### **TBI Fund Updates**

Margaret Lumia, PhD, MPH Administrator, Disability Health & Wellness/TBI Fund

### **TBI Fund Applicants**

#### **2024 Quarter 4**

#### **New Applicants (18)**

√ 10 Female, 8 Male

#### **Top County**

✓ Monmouth (n=3)

#### Race/Ethnicity

- ✓ White (n=9)
- √ Hispanic (n=2)
- ✓ Black (n=4)
- ✓ Asian (n=1)
- ✓ Prefer not to say (n=1)

#### **Top Causes**

- ✓ MVC (n=9)
- ✓ Struck-by (n=4)
- ✓ Falls (n=3)

#### **2025 Quarter 1**

#### **New Applicants (14)**

√ 4 Female, 10 Male

#### **Top County**

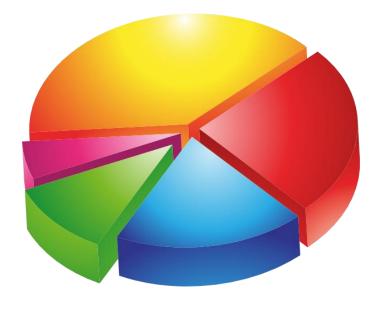
✓ Monmouth (n=3)

#### Race/Ethnicity

- $\checkmark$  White (n=12)
- ✓ Black (n=1)
- ✓ Prefer not to say (n=1)

#### **Top Causes**

- ✓ Falls (n=8)
- ✓ MVC (n=3)
- ✓ Struck-by (n=1)
- ✓ Gunshot (n=1)





### **TBI Fund Updates**

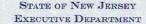
To date, for State Fiscal Year 2025, the TBI Fund has **collected \$2.897m** from the \$.50 MVC Vehicle Registration Surcharge.

To date for State Fiscal Year 2025, TBI Fund has **paid \$1,313,513.15** for direct and case management services

The Top Three Service Providers include:

- ➤ Olive Branch (\$260,313)
- > A Plus (\$187,672)
- ➤ Advancing Opportunities (\$131,568)

March was Brain Injury Awareness Month.





WHEREAS, 2.8 million Americans sustain a traumatic brain injury each year, and an estimated 5.3 million Americans are living with disabilities caused by brain injury, and

WHEREAS, there are more than 200,000 hospitalizations related to traumatic brain injuries each year, and nearly 70,000 Americans die annually as a result of traumatic brain injury; and

WHEREAS, in New Jersey, approximately 12,000 - 15,000 individuals sustain brain injuries from traumatic events annually, of which 1,000 are fatal; and

WHEREAS, there are an estimated 175,000 New Jersey citizens who have disabilities resulting from a traumatic brain injury; and

WHEREAS, the highest rates of traumatic brain injury occur among individuals under 35 years of age and rise sharply after age 65; and

WHEREAS, people with a brain injury often have perceptual, physical, emotional and/or psychiatric problems with a combination of cognitive impairment; impaired interpersonal skills, memory loss, impaired problem solving skills, slowness in thought processing, speech disorders, physical deficits and epilepsy; and

WHEREAS, the only cure for a brain injury is prevention, and public awareness is critical to achieve that goal, as well as to enhance the recovery process of all persons affected by a brain injury; and

WHEREAS, Brain Injury Alliance of New Jersey provides education, outreach, prevention, advocacy and support services to all persons affected by a brain injury and to the general public;

WHEREAS, the Department of Human Services, Division of Disability Services administers the Traumatic Brain Injury Fund, offering services and supports to eligible NJ residents living with a TBI;

NOW, THEREFORE, I. Phillip D. Murphy, Governor of the State of New Jersey, do hereby proclaim:

#### MARCH 2025 AS BRAIN INJURY AWARENESS MONTH

in New Jersey.



GIVEN, under my hand and the Great Seal of the State of New Jersey, this eighteenth of March in the year two thousand twentyfive, the two hundred forty-ninth year of the Independence of the United States.





# TBI, Concussion, and Aging (Oh my!)

Cathy Trapani and the NJ TBI Survivor Board



### Motivation

- Many of the supports for TBI are aimed at specific age or demographic groups.
- Those living with TBI often have personal difficulties and systemic difficulties across transitions.
- Living with TBI, PCS, and longevity of TBI-related conditions
  - Loss of Support structures over time, eg. Divorce
- Bring attention to specific age-related issues for consideration in developing the State Action Program.



### Concussion and Age

- When you hear "concussion" as opposed to "TBI", do any stereotypes come to mind?
  - Age, Athletes, Motor Vehicles, Domestic Violence, for example?
- Are these stereotypes accurate?

 Usual problems with getting actual numbers -- only hospital admissions and subsequent deaths or possibly death certs.



**TABLE 1** – Annual number and rate per 100,000 of traumatic brain injury-related deaths<sup>†</sup> by selected socio-demographic characteristics — National Vital Statistics System, United States, 2018 and 2019

Socio-Demographic Characteristic	2018 Number	2018 Rate* (95% CI)	2019 Number	2019 Rate* (95% CI)
Age (Years)				
Birth-17	2,493	3.4 (3.3-3.5)	2,476	3.4 (3.3-3.5)
Birth-4	659	3.3 (3.1-3.6)	612	3.1 (2.9-3.4)
5-9	248	1.2 (1.1-1.4)	270	1.3 (1.2-1.5)
10-14	456	2.2 (2.0-2.4)	497	2.4 (2.2-2.6)
15-24	6,688	15.6 (15.2-16.0)	6,417	15.0 (14.7-15.4)
25-34	7,376	16.2 (15.8-16.5)	7,251	15.8 (15.4-16.1)
35-44	6,041	14.7 (14.3-15.0)	6,110	14.7 (14.3-15.0)
45-54	6,780	16.3 (15.9-16.7)	6,536	16.0 (15.6-16.4)
55-64	8,250	19.5 (19.1-20.0)	8,057	19.0 (18.6-19.4)
65-74	7,473	24.5 (24.0-25.1)	7,542	24.0 (23.4-24.5)
75+	16,591	75.7 (74.5-76.8)	17,314	76.7 (75.6-77.8)

Source: CDC Surveillance Report 2022

### Mechanism of death and age

- Suicide accounted for 35.5% of TBI-related deaths and an average annual rate of 7.2 per 100,000 population.
  - The average annual rates attributable to suicide were **highest** among older adults **aged 75+ years** (12.2 per 100,000 population).
- Unintentional falls accounted for 29.9% of all TBI-related deaths, with an average rate of 4.6 per 100,000 population.
  - Older adults aged 75+ years had the **highest** average annual rate (54.3 per 100,000 population) of TBI-related deaths attributable to unintentional falls. This rate was over five times higher than that among those aged 65-74 years (average annual rate of 9.5 per 100,000 population).



### TBI and Age

- People age 75 years and older
  - had the highest numbers and rates of TBI-related hospitalizations and deaths
  - account for 32% of TBI-related hospitalizations and 28% of TBI-related deaths.
- **CDC Guideline**: Healthcare providers should check for signs and symptoms of TBI if an older adult has 1) Fallen or has a fall-related injury, or 2) Been in a car crash.
- A single fall is now a risk factor for subsequent falls.
- Researchers have observed a tendance among people 65+ with TBI to be white females who have had a fall.
- In 2006, there were 80,000 ED visits for TBI among those 65+, resulting in 80% being admitted to the hospital.





#### Physical

- · Bothered by light or noise
- Dizziness or balance problems
- Feeling tired, no energy
- Headaches
- Nausea or vomiting (early on)
- Vision problems



#### Thinking and Remembering

- Attention or concentration problems
- Feeling slowed down
- Feeling foggy or groggy
- · Problems with memory
- Trouble thinking clearly



#### Emotional

- Anxiety or nervousness
- Irritability or easily angered
- Feeling more emotional
- Sadness



#### Sleep

- Sleeping less than usual
- · Sleeping more than usual
- Trouble falling asleep





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- Sleeping more than usual
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### Scenarios

- Diagnosed with a TBI at a "young" age
  - Progression of TBI recovery unknown over longitudinal studies
  - Possible 40+ years of TBI as they approach retirement
- Diagnosed with a TBI in "middle" age
  - Age (50+) is a risk factor for Post-concussive syndrome
- Diagnosed with a TBI as a "senior citizen"
- Fatigue Factor
  - Because of confounding symptoms attributed to either TBI or aging, TBI mostly gets harder to manage.



### Long-term care and chronic condition

- "injury to the brain can evolve into a lifelong health condition termed chronic brain injury (CBI). CB impairs the brain and other organ systems and may persist or progress over Individual's lifespan.
- CBI must be identified and proactively managed as a lifelong condition to improve health, independent function and participation in society" (Corrigan and Hammond, 2013)
- Recommendations include the need for a disease management approach or Care Model (CCM), where health system and community resources interact at the system and provider levels to support patient selfmanagement and improve outcomes.



### Confounding Issues

- TBIs may be missed or misdiagnosed in older adults because symptoms
  of TBI overlap with other medical conditions that are common among
  older adults, such as dementia... and vice versa.
- "Doctor Auto-Pilot"
  - Specialists
  - Reason for Visit
  - Lack of resources and time
  - Best practices are constantly changing
    - Chronic condition
    - Causes
    - Treatments

"If all you have is a hammer, everything looks like a nail" highlights the concept of the "law of the instrument," or the "law of the specialist."



The increase in the aging population in the United States and the prevalence of TBI in this demographic group have led to growing recognition of TBI as an important issue for older adults (Flanagan et al., 2005; Peters, 2020). Yet the effects of **age on recovery from TBI remain understudied**, and clinical guidelines for care of elderly people with TBI are underdeveloped (Stein et al., 2018). For example, Gardner and colleagues (2018, p. 890) found that "despite the large and growing epidemic of older adults with incident TBI, there are **few to no evidence-based geriatric TBI guidelines** to inform complex medical decisions for ether acute or long-term management.

Of particular concern is the number of **TBIs occurring in older adults as a result of falls**. According to the Centers for Disease Control and Prevention (CDC), falls are the **leading cause of TBI (51 percent)** for older adults. **Age-related changes, such as frailty, balance problems, joint problems, medical comorbidities, and medications, can increase fall risk** (Cefalu, 2011).

In addition, changes in the brain occur with aging (Gardner et al., 2018). Distinguishing between mild cognitive impairment due to aging and cognitive effects arising from a mildTBI can be challenging,16 while underserved seniors can reportedly also be "misdiagnosed as having dementia and are deemed not candidates for intensive rehabilitation."17



### The Elephant in the Room

- Gottlieb, S., 2000. Head injury doubles the risk of Alzheimer's disease. BMJ, 321(7269), p.1100.
- Traumatic brain injury (TBI) is associated with an increased risk of developing dementia later in life,
  - Moderate to severe TBIs have a more pronounced link to dementia compared to mild TBIs.
  - The risk appears to be higher for individuals with multiple TBIs.
- Studies suggest that TBIs sustained earlier in life may be associated with a greater risk of dementia compared to those sustained later in life.
- Outcome studies of msTBI show about 1/3 decline after previously reaching a plateau



### Healthy Aging

• UN General Assembly declared <u>2021–2030</u> the <u>UN Decade of Healthy Ageing Global collaboration</u>: governments, civil society, international agencies, pros, academia, the media and the private sector for 10 yrs of <u>concerted</u>, <u>catalytic and collaborative action</u> to foster **longer and healthier lives**.

#### Four areas:

- Changing how we think, feel and act towards age and ageism;
- Developing communities in ways that foster the abilities of older people;
- Delivering person-centered integrated care and primary health services responsive to older people;
- Providing older people who need it with access to quality long-term care.



- Recommendations

   Explicitly develop relations between state agencies at transition points.
  - School-age to adulthood; Military to veteran; working to retired/disabled
  - "Adult" to senior citizen
- Develop special educational resources for Seniors:
  - Mental Health Resources
  - Falls and TBI
  - Motor Vehicles and TBI
- Study TBI Fund Guidelines for lifetime caps on expenditures and maximum number of years



### Ideas for exploration

- Transportation and/or companions?
  - Vouchers?
  - Aide on Access Rides (similar to the additional aide on school buses)
- Patient advocates, specially trained for TBI, attached to patient, not health facility?
- Home health care aides?
- TBI-specific environment for PT, OT, Speech, Vocational?
- Routines and technology -- high school students?
- Case Managers for all citizens with TBI who wish one?















### State Action Plan Development & Discussion

Kelly Miller, Senior Manager for Technical Assistance NASHIA

## New Jersey State Plan on Traumatic Brain Injury

April 15<sup>th</sup>, 2025

Kelly Miller: kmiller@nashia.org





### Topics for Today

- Updates
  - Restructuring
  - Language
- Sustainability and Evaluation
- Timeline
- Questions



### Updates

- Workgroup Restructuring
  - Infrastructure and Access moved internally
  - Created Experience Informed Solutions workgroup
  - Education and Awareness
  - Equity and Inclusion
- Language
  - Shifting some words to broader terms based on federal orders related to DEI
    - Disadvantaged=Under resourced



### Workgroup Roster

#### **EQUITY AND INCLUSION**

**Jack Tetters** 

Thompson

Virgilio Caraballo

Robert Robinson

Tara Buggie

**SAKINA LADHA** 

Porsha Moody

Katrina Majewski

Adam Neary

Chris Mueller

Peter Wick

Renee Caratozzolo

Katherine Hempstead

Tanya Gautheir

Jennifer Underwood

### EDUCATION AND AWARENESS

Ryan Carter

Barbara Chabner

Matt Collura

Cathy Trapani

James McGhee

Jacque Moskowitz

**SOPHIE WILKINSON** 

Patricia Thompson

Malachi Gaddy

Lisa Joyce

Gregory Przybylski

Jean Lengenfelder

Barbara Young

Inger Magnusson

#### **EXPERIENCE INFORMED SOLUTIONS**

Sandra Barnett Erica Cooper

Ginamarie Williams

Wendy Berk

#### INFRASTRUCTURE AND ACCESS

Margaret Lumia Sakina Ladha

Sophie Wilkinson



### 2024-2025 Timeline

April December **February** June August November 82 81 82 May July January March **Visioning Objective Action step Goal creation** Workgroup development **Focus on** planning **FINALIZE** leads evaluation AND identified Workgroups Workgroups and Workgroups **CELEBRATE!** share sustainability share share Goal progress progress progress brainstormin



### Sustainability

0

- Design and set up a program in a way that it can continue to operate independently and achieve its goals over the long term.
- How might this look in the state planning process and document:
  - Describes a process for measuring and documenting actions that build collaboration and sustainability of services and supports
  - Provides strategies to support collaboration among relevant partners and agencies
  - Includes recommendations for policy development for coordinated systems of services and supports
  - Identifies a collaborative interagency structure for building and maintaining interagency support, planning, and problem solving
  - Includes components to address sustainability of programs, services, and supports

https://www.nashia.org/resources-list/strong-infrastructure-components-for-brain-injury-bi-state-self-assessment-tool





### Evaluation

- How do we know things are working?
- How might this look in the state planning process and document?
  - Incorporates a mechanism for structured feedback to promote continued dialogue and evaluation among partners
  - Functions as a living document and is reviewed on a regular basis
  - Becomes a vehicle to assess potential feasibility, relevance, and evaluation of existing efforts and new initiatives.





### Strategies for Sustainability's Evaluation

- Training and follow up
  - Training evaluations, offering refresher/booster training, offering next level training
- Seeking out champions
  - Preparing and supporting champions
- Thoughtful implementation from the start
  - Thinking about small steps (scaling up)
- Tracking information/data
  - What information is already collected? What information systems already exist?
  - Sharing information/accomplishments
- System level
  - Creating policy, new procedures, referral processes





### May Meeting Focus

#### Breakout groups

Continue to work on finalizing goals and objectives

#### Things to keep in mind when writing objectives

- Use action words
- State the intended outcome (the process will be broken down into action steps under the objective)
- Consider stating who the identified community/population is related to the objective
- You can think long term since your state plan will remain in place for several years





### **Upcoming Webinar**



The Link Center invites you to participate in its Shared Learning Groups virtual gathering series. Please join us for our next Shared Learning Groups as we discuss "Developing Regulation and Coping Skills".

We all have ups and downs in life, and how we handle those feelings is called emotion regulation. It's about being able to control our emotions on purpose. People with intellectual and developmental disabilities (I/DD), brain injuries, and other disabilities and co-occurring mental health conditions and the people who support them may benefit from being aware of and learning ways to maintain their wellness during challenging or confusing times. This session will focus on those ways to be more aware and will also present strategies and tools to help people manage their emotions.

Live Captioning and ASL Interpretation will be provided during all live webinars.

Registration is required.





# Registration Information April 22, 2025

Direct Support Professionals: 1:00-2:30p EST

Register in advance for this webinar:

<a href="https://nasddds-">https://nasddds-</a>
<a href="org.zoom.us/webinar/register/WN U-XGj3PcQPisMbBpbAcSUQ">org.zoom.us/webinar/register/WN U-XGj3PcQPisMbBpbAcSUQ</a>

Clinical Professionals: 3:00-4:30p EST

Register in advance for this webinar:

<a href="https://nasddds-">https://nasddds-</a>
<a href="mailto:org.zoom.us/webinar/register/WN\_lxNc3VSGRK">org.zoom.us/webinar/register/WN\_lxNc3VSGRK</a>
<a href="https://nasddds---">-tt0Mcat7m-Q</a>

#### April 23, 2025

Families of people with lived experience: 1:00-2:30p EST

Register in advance for this webinar:

<a href="https://nasddds-org.zoom.us/webinar/register/WN\_rFUY-pstTzC0mgfHY\_JnvQ">https://nasddds-org.zoom.us/webinar/register/WN\_rFUY-pstTzC0mgfHY\_JnvQ</a>

People with lived experience: 3:00-4:30p EST

Register in advance for this webinar:

<a href="https://nasddds-">https://nasddds-</a>
<a href="mailto:org.zoom.us/webinar/register/WN\_anV3TxBYR8">org.zoom.us/webinar/register/WN\_anV3TxBYR8</a>
<a href="mailto:ms-Pcww6V6bw">ms-Pcww6V6bw</a>





### Questions?

Next Meeting May 14th, 2025 1:00pm















#### **Upcoming Meeting Schedule:**

- ➤ May 31, 2025- State Action Plan Meeting
- > June 11, 2025- State Action Plan Meeting
- > July 15, 2025- NJ Advisory Council on TBI Meeting
- > August 13, 2025- State Action Plan Meeting
- > October 21, 2025- NJ Advisory Council on TBI Meeting
- > November 12, 2025- State Action Plan Meeting
- > December 10, 2025- State Action Plan Meeting



