

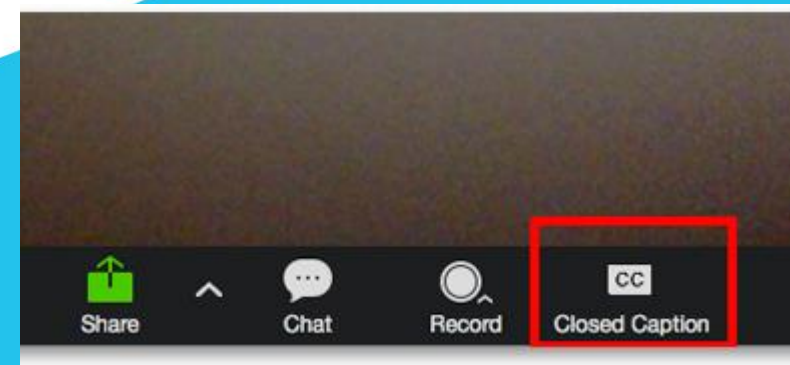
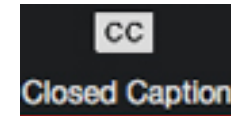


# New Jersey Advisory Council on Traumatic Brain Injury

July 23, 2024

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- On your screen, you should see the button on the bottom.
- Click on it to follow captioning.



# Agenda



**Welcome, Introductions, Review of Minutes, Division Updates:** 10:00am-10:05am  
*Peri L. Nearon, MPA, Executive Director, DDS*

**NJ TBI State Partnership Program (NJTBI SPP):** 10:05am-10:35am  
*Sakina Ladha, MD, MPH, Project Director*

**State Action Plan Development:** 10:35am-11:35am  
*Sakina Ladha, MD, MPH, Project Director*

**Break:** 11:35am-11:40am

**Brain Injury Alliance of NJ:** 11:40 am- 11:45am  
*Barbara Chabner, Director of Education & Outreach*

**TBI Fund Updates:** 11:45am-11:50am  
*Jacqueline Moskowitz, Assistant Director*

**Open Discussion:** 11:50am-12:00pm





# **Welcome, Introductions, Review of Minutes, Division Updates**

Peri Nearon

Division of Disability Services

10:00 – 10:05



# **New Jersey TBI State Partnership Program**

Sakina Ladha, MD, MPH

Project Director

10:05 - 10:35



# **State Action Plan Development**

Sakina Ladha, MD, MPH

Project Director

10:35 - 11:35



# State Action Plan Examples

NJ TBI Advisory Board & Council State  
Action Plan Development Meeting



# New York State Traumatic Brain Injury Five-Year Action Plan (2012)

- **Purpose of the Plan:**

- "Address the increasing demand of a cost effective system of care for children and adults who have traumatic brain injuries"

## **Highlights:**

- Provides detailed background on many groups impacted by TBI (youth, survivors of DV, justice system, veterans, etc.) and how the plan aims to improve their experience with TBI care.
- Clearly outlines gaps related to actionable recommendations, providing reasoning behind the plan.



### Education and Prevention

Due to the incidence and cost burden of TBI, the CDC and NYS have made TBI education and prevention a priority, resulting in public/private collaborative efforts to increase knowledge about TBI. The efforts include distribution of tool kits, targeted to students, school nurses and faculty, coaches, and physicians. These materials have been distributed by DOH, the Brain Injury Association of New York State (BIANYS) and other organizations throughout New York. Similar materials specific to New York State have been developed by the DOH Injury Prevention Program and are being distributed throughout the State.<sup>15</sup>

In October 2011, the CDC activated an on-line TBI training program for clinicians, following the curriculum previously developed specifically for athletic coaches. The training programs are also available free of charge on the CDC website. In addition, CDC is establishing an advisory group to develop guidelines for pediatric treatment of mild TBI for issuance by 2013.<sup>16</sup>

### Children, Youth and Sports

The cause of TBI in children varies according to age group. Cases of TBI in infants and toddlers are primarily caused by falls, abuse, and neglect.<sup>17</sup> Early elementary aged children sustain TBI primarily from falls and pedestrian motor vehicle accidents. Older elementary children, through middle school age, sustain TBI mainly as the result of pedestrian related bicycle or motor vehicle accidents and sports. High school youth sustain TBI largely from motor vehicle accidents, assaults and sports.<sup>18</sup> Although common in organized athletic activities, a concussion may occur anywhere, including the playground or backyard.

The importance of proper recognition and management of concussion has emerged as essential to recovery and the prevention of further brain injuries. Research now indicates that both cognitive and physical rest are crucial for recovery from a TBI. Appropriate rest is especially important to avoid a phenomenon known as "second impact syndrome" (SIS) whereby a successive brain injury occurs before recovery from an earlier one is complete.<sup>19</sup> The consensus of TBI experts convened at the 2008 Zurich International Conference on Concussion in Sport, is that the "cornerstone of concussion management is physical and cognitive rest until symptoms resolve, and

# North Carolina State Action Plan for People With Traumatic Brain Injury (2017)

- **Purpose of the Plan:**

- "Improve access to appropriate specialized services and supports and increase knowledge and awareness about brain injuries among and adults, their families, and providers"

## **Highlights:**

- Goals and objectives are clear and broken down into specific measures to ensure understanding.
- Specifies key organizations and their role in the five-year action plan.

## **GOAL 1: DATA COLLECTION TO SUPPORT PLANNING EFFORTS**

Develop a systematic data collection process with stakeholder input to demonstrate the incidence of TBI and the need for specific habilitative and rehabilitative interventions using evidenced-based outcome data in North Carolina:

**Objective 1.** Increase awareness and education among key stakeholders of incidence, needs, and specialized service models for North Carolinians living with TBIs.

*Measure 1:* Implement an education campaign targeted towards elected officials and state agencies that increases awareness and understanding of the continuum of TBI across the lifespan of people with such injuries, their families, and communities.

*Measure 2:* Engage interested stakeholders and advocacy groups for education and collaboration.

*Measure 3:* Educate key stakeholders on best practices for the continuum of care for people with TBIs.

*Measure 4:* Educate key stakeholders on the need for increased funding for best practices throughout the continuum of care.

# Colorado Mindsource Brain Injury Network State Plan (2020)

- **Purpose of the Plan:**

- "Create and strengthen a system of services and supports that maximize the independence, well-being, and health of people with brain injuries"

## Highlights:

- Outlines the Advisory Board Meeting activities throughout the development of the plan.
- Notes specific barriers in Colorado BI care which aim to be addressed by the 5-year action plan.



## Goals & Strategies

The Advisory Board was tasked with creating a plan to address the identified gaps in the system. Per the Koné Study that was completed in 2017, there are several barriers that create difficulties in accessing supports:

- There are no standardized screening and identification protocols to identify a brain injury.
- There is little public awareness about brain injuries, which impacts prevention and reinforces stigma.
- Providers need better training on the symptoms of brain injury to avoid differential diagnoses for individuals.
- Access to services is prevented by cost and health insurance limitations due to high out-of-pocket expenses.
- Divided payer and service structure create access barriers, especially between primary/medical care and behavioral health care.
- Disparate systems are hard for individuals and service providers to navigate, and make it difficult to understand what services are available and how they can be accessed.
- There is little-to-no coordination among service providers. Communication and information sharing aren't consistent, often because of technology constraints and broader system silo issues.

Date	Advisory Board Activities
	<p>can be leveraged during the implementation of the plan</p> <ul style="list-style-type: none"><li>• Working groups reviewed their revised goals and strategies and made changes as needed</li></ul>
April 2019	<ul style="list-style-type: none"><li>• A focus group was held with partners that work closely with MINDSOURCE to glean initial reactions and recommendations for the Advisory Board to consider.</li></ul>
May 2019	<ul style="list-style-type: none"><li>• The Advisory Board was trained on Person-Centeredness and Cultural Competency</li><li>• Working groups shared changes to their work plan and discussed objectives as a result of the feedback received from the focus group in April 2019.</li></ul>
August 2019	<ul style="list-style-type: none"><li>• The Advisory Board heard and discussed the feedback received from participants of the focus groups that were held in June and July 2019 (see note below this exhibit) as well as input gleaned from on-line surveys. As a result, they updated the language and clarified some of the items included in the state plan</li></ul>

# IOWA State Plan for Brain Injury (2021)

- **Purpose of the Plan:**

- "Reduce the occurrence of brain injury and to improve outcomes for those who have sustained one"

## **Highlights:**

- Organizes plan into four key areas of focus, creating a clear outline and direction for the plan.
- Layout of the plan allows individuals with a range of comprehension levels to easily navigate and understand the plan.



## Individual & Family Access



## Service System Enhancements



## Prevention



## Awareness & Education

### Focus Area 2:

## Service Systems Enhancements



In recent years, Iowa has made improvements for meeting the needs of individuals with brain injury, specifically for treating neurobehavioral symptoms, improving treatment outcomes and reducing out-of-state placements. However, individuals with brain injury, their families and many service providers continue to report a variety of unmet needs. Training of direct support professionals about the unique needs and challenges individuals with brain injury and their family experience remains a priority.

**Goal 4:** Develop service recommendations to meet the needs of Iowans with brain injury.

- Evaluate the brain injury service system including gaps in care and barriers to services in Iowa.
- Report findings and recommendations resulting from the brain injury service system evaluation.
- Prioritize actionable recommendations from the service system evaluation report to address service gaps and barriers

# Massachusetts Brain Injury Strategic Plan (2023)

- **Purpose of the Plan:**

- "Support underserved populations, communities, and those with co-occurring conditions including behavioral health diagnoses [in the context of brain injury]. "

## Highlights:

- Provides comprehensive background on TBI supporting the importance of plan implementation.
- Highlights the current state resources available to those with TBI in MA.



## Summary of Massachusetts Data (2016-2018)

**8,831  
HOSPITAL  
STAYS**

There was an average of **8,831** hospital stays and nearly **63,000** emergency department visits associated with a traumatic brain injury annually among MA residents for the time period studied.

**67%**

The leading most common mechanism of injury was unintentional fall accounting for **67%** of TBI-related inpatient stays and approximately **51%** of emergency department visits.

**70  
YEARS**

TBI-related hospital stays were highest among adults **70 years** of age and older.

**0-2  
YEARS**

Children **0-2 years** of age had the highest rate for TBI-related emergency department visits.

**MOST  
GO  
HOME**

Although most persons with TBI treated in the inpatient setting were discharged home, a sizable proportion of older adults were discharged to skilled nursing facilities.



## What state resources exist?

**T**he Statewide Head Injury Program (SHIP) was established in 1985 within the Massachusetts Rehabilitation Commission (MRC) as a result of grassroots advocacy efforts. It was the first national model for publicly funded services for individuals with traumatic brain injury (TBI) and is the lead brain injury agency in the Commonwealth.

SHIP was established by 107 CMR 12.04 in 1985. To be eligible for SHIP services, an individual must have an externally caused TBI with related cognitive, physical and/or behavioral impairments and be able to participate in community-based services. Services are funded through a combination of state appropriations, SHIP account (budget line item 4120-6000), the Head Injury Treatment Services (HITS) Trust Fund (budget line item 4120-6002), Medicaid funding for specific programs, and government line items.

# Missouri Traumatic Brain Injury: Five Year Plan (2024)

- **Purpose of the Plan:**

- "Create and strengthen person-centered and culturally competent systems of services and supports to maximize the independence and well-being of people with TBI across the state"

## Highlights:

- Clearly outlines the methodology used to develop the plan from phase one to plan implementation.
- Activities from each goal are assigned to specific stakeholders and potential partners.

## Goal 2: Enhance diversity and reach of the MO Brain Injury Advisory Council (MBIAC).

### *Year 1 Activities:*

1. Increase survivor membership and engagement in MBIAC; foster recruitment through partnerships and support groups.\*
2. Recruit representation from Centers for Independent Living (CILs) and Protection & Advocacy to serve on MBIAC.\*
3. Participate in monthly National workgroups to learn about programmatic and systems best practices.\*

### *Years 2-5 Activities:*

1. Continue MBIAC member survey to monitor progress and ensure diverse representation.\*
2. Recruit representation from leadership in Aging field to serve on MBIAC.
3. Recruit representation from Veteran community to serve on MBIAC.
4. Establish partnerships with outdoor/recreational groups and initiatives to provide unique opportunities for TBI survivors to participate in outdoor programming and activities.\*
5. Develop accessible board training and resource kit.\*
6. Create sustainability plan for funding activities beyond grant period using Program Assessment Sustainability Tool (PSAT).\*

\*Funded grant activities

### *Stakeholders and Potential Partners:*

Individuals with lived experiences and families as well as BIA-MO, DHSS-ABI, UMKC-IHD and MBIAC

## Methodology

The development of Missouri's Five-Year Brain Injury State Plan took place over the course of a year and was divided into three primary phases. Each stage supported a data-driven and representative final product.

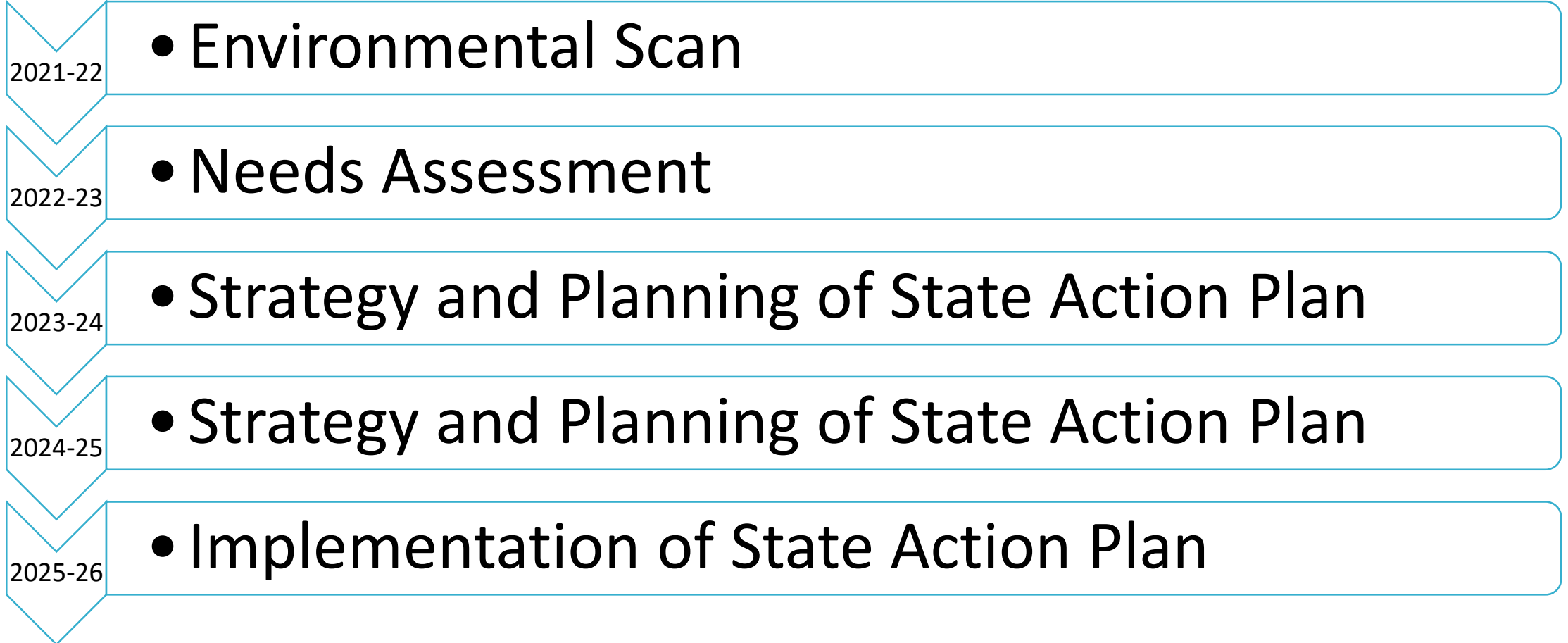
In **Phase One**, the grant team reviewed past Missouri State Plans to solidify an understanding of previous plans and to identify opportunities for continuity. The team then compiled TBI state plans from other grantee states to compare their plans. This process promoted an understanding of common national TBI priorities and provided context for activities to be translated into a Missouri context. This provided a foundation for making structural and content updates to the state plan.



# Meeting rules:

- Respectfully engage and listen to discussions by allowing one member to speak at a time;
- Address differences in opinion in a thoughtful and respectful manner;
- Adhere to meeting agenda timeframes and refrain from disrupting Council meetings;
- Any accommodations for clarity or support among Council Members will be acknowledged and addressed.

# Grant Timeline



# What is the purpose of the grant?

- The state must address four barriers to needed services by:
- Screening to identify individuals with TBI
- Building a trained TBI workforce by providing professional training
- Providing information about TBI to families and referrals to appropriate service providers
- Facilitating access to needed services through resource facilitation

# What is the purpose of the state action plan?

The purpose of the State Action Plan is to:

- Guide continued progress in assisting New Jerseyans who live with TBI and their families;
- Address the need for TBI prevention; and
- Improve access to needed care and services so that individuals may return to community life after an injury.

# Role of NJTBI Council and NJTBI Survivor Board

- Support DDS in effectively identifying gaps in services and supports,
- Develop a responsive plan to address these gaps,
- Collaborate across private and public partners to meet the needs of the NJ TBI community across the lifespan,
- Create and monitor efforts related to a statewide plan on brain injury which serves as a blueprint to guide the work of the DDS and related boards and councils,
- Monitor these efforts as applicable.



# State Plan Focus Areas

1. Equity and Inclusion
2. Infrastructure and Access
3. Education and Awareness

# State Action Plan Examples

# Action Plan Timeline

## Stage 1

- Needs Assessment
- Establishment of task force (board and council)

## Stage 2

- State Action Plan

## Stage 3

- Action Plan Conference
- Implementation Agenda

# Stage 1: Task Force Establishment

- July – October 2024
  - Set up monthly meetings starting October 2024
    - 2-hour meetings once a quarter
    - 1-hour meetings monthly in between
  - Add new members to the board and council focusing on diversity and inclusion.
  - Hire a facilitator to assist the task force.

# Stage 2: Action Plan

- October – December 2024
  - Define priority areas and goals based on results of the needs assessment and brain-storming session.
- January – April 2025
  - Outline the strategies to reach desired outcomes based on priority areas and goals.
- May – August 2025
  - Engage stakeholders to include in the action plan to achieve target outcomes.

Component 4	Basic	Intermediate	Advanced
<b>State Plan</b>  <p>The state plan determines how to best improve the services and supports for people living with BI. Plans include goals for addressing unmet needs and sustaining current initiatives in the state. State plan oversight lies with the lead state agency; however, full implementation requires multiple partners.</p>	<b>The Plan:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Incorporates specific timeframes</li> <li><input type="checkbox"/> Reflects the needs and resources assessment results and other available data</li> <li><input type="checkbox"/> Involves strategic partners, individuals with BI, family members in development</li> <li><input type="checkbox"/> Reflects the needs prioritized by people with BI and family members</li> <li><input type="checkbox"/> Describes a person-centered, person- and family-directed, and culturally competent framework related to desired service delivery</li> </ul>	<b>The Plan:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Describes a process for measuring and documenting actions that build collaboration and sustainability of services and supports</li> <li><input type="checkbox"/> Utilizes SMART (Specific, Measurable, Attainable, Relevant, and Time-based) objectives</li> <li><input type="checkbox"/> Provides strategies to support collaboration among relevant partners and agencies</li> <li><input type="checkbox"/> Cites relevant historical information and justification for activities</li> <li><input type="checkbox"/> Incorporates a mechanism for structured feedback to promote continued dialogue and evaluation among partners</li> <li><input type="checkbox"/> Includes recommendations for policy development for coordinated systems of services and supports</li> <li><input type="checkbox"/> Incorporates available data in the assessment of needs and resources</li> </ul>	<b>The Plan:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Promotes and reflects interagency buy-in through MOUs or MOAs, letters of commitment, or mandated involvement from other agencies involved</li> <li><input type="checkbox"/> Identifies a collaborative interagency structure for building and maintaining interagency support, planning, and problem-solving</li> <li><input type="checkbox"/> Functions as a living document and is reviewed on a regular basis</li> <li><input type="checkbox"/> Becomes a vehicle to assess potential feasibility, relevance, and evaluation of existing efforts and new initiatives.</li> <li><input type="checkbox"/> Includes components to address sustainability of programs, services, and supports</li> </ul>

# Brainstorming guidelines

- No criticism, evaluation, judgement, or defense of ideas during this session.
- The more ideas, the better.
- Encourage out of the box thinking.
- Build on each other's ideas.
- We will spend 10 minutes per question and then move on to the next.

# Equity and Inclusion

- What changes would you like to see in NJ to enhance equity in the TBI space?

## REMEMBER:

- Everyone's thoughts are valued.
- Voice your thoughts.
- Give others a chance to speak.
- Take a break if you need!



- How could healthcare, public service, and community organizations create a more inclusive environment for individuals with TBI?

**REMEMBER:**

- Everyone's thoughts are valued.
- Voice your thoughts.
- Give others a chance to speak.
- Take a break if you need!

# Infrastructure and Access

- What improvements are needed in NJ's infrastructure to better support individuals with TBI?

**REMEMBER:**

- Everyone's thoughts are valued.
- Voice your thoughts.
- Give others a chance to speak.
- Take a break if you need!

- How can access to essential services for individuals with TBI be improved in NJ?

**REMEMBER:**

- Everyone's thoughts are valued.
- Voice your thoughts.
- Give others a chance to speak.
- Take a break if you need!

# Education and Awareness

- Who should education and awareness be targeted to?

## REMEMBER:

- Everyone's thoughts are valued.
- Voice your thoughts.
- Give others a chance to speak.
- Take a break if you need!

- What initiatives would you recommend to increase education and awareness about TBI in NJ?

**REMEMBER:**

- Everyone's thoughts are valued.
- Voice your thoughts.
- Give others a chance to speak.
- Take a break if you need!



# Break

11:35-11:40



# Brain Injury Alliance of New Jersey

## Update (April – June 2024)

Barbara Chabner  
Director of Education and Outreach



11:40 - 11:45

# Workshops

- In-person and virtual workshops
- 115 workshops, 5000+ attendees
- Wide range of topics and settings
- 19 counties
- Fiscal Year: 320 workshops, 12,000 attendees



# Exhibiting and Coalition Meetings

- Professional Conferences
- NJSHA (Speech-Language-Hearing Association)
- Community Fairs/Wellness Events (34 attended)
  - Bergen, Monmouth, Mercer, Union, Middlesex, Essex, Ocean, Atlantic, Sussex, Burlington, Camden, Passaic
- Fiscal Year: 100 (includes 17 NNO and 8 professional conferences)
- Community Coalition Meetings (55 attended)
- Coalition meetings
- Individual networking meetings
- Fiscal Year: 220 attended

# BIANJ Annual Professional Seminar

- Bridging the Disparity Gap: Improving Equity in Brain Injury Care and Prevention
- Dr. Kelli Gary Talley - brain injury survivor, professor, researcher, advocate – delivered keynote address;
- 9 workshops; 20 student posters; 28 exhibitors
- CEUs for multiple disciplines; first time for CMEs
- 214 attended; multidisciplinary
- Sharon Naulty received the **Mimi Goldman Positive Achievement Award**

# Webinars and Facebook Live

- Hosted 3 webinars
- 286 attended
- Fiscal Year: 11 webinars, 1,021 attendees
- Facebook Live Discussions
- Introducing the **New BIANJ Resource App**
- Fiscal Year: 8 Facebook Live sessions



# TBI Fund

- TBI Fund promoted at presentations/events
- 72 referrals
- Fiscal Year: 262 referrals

# Publications

- Brain Injury and substance use handout
- Concussion guide updates



# TBI Fund Updates

Margaret Lumia, PhD, MPH

Administrator, Disability Health & Wellness/TBI Fund

11:45 - 11:50

# 2024 TBI Fund Fiscal Updates

The total Annual Traumatic Brain Injury fund budget is supported by a 50 cent surcharge on every New Jersey motor vehicle registration fee.

## For FY24...



TBI Fund is projected to collect **\$4 million in revenue.**



TBI Fund has processed **\$1.6 million in payments to service providers** for direct services to clients.



TBI Fund has processed **\$350,000 for Case Management** services.



To date, the TBI Fund has collected **\$37,000 in lien recoveries.**

*\*Expenditures do not reflect all of FY24 payments as we continue to process invoices to close out the fiscal year.*

# TBI Fund Applicants

Since the Last Council Meeting (April 16, 2024)

## 16 New Applicants

- ✓ 6 Female, 10 Male

## Top Counties

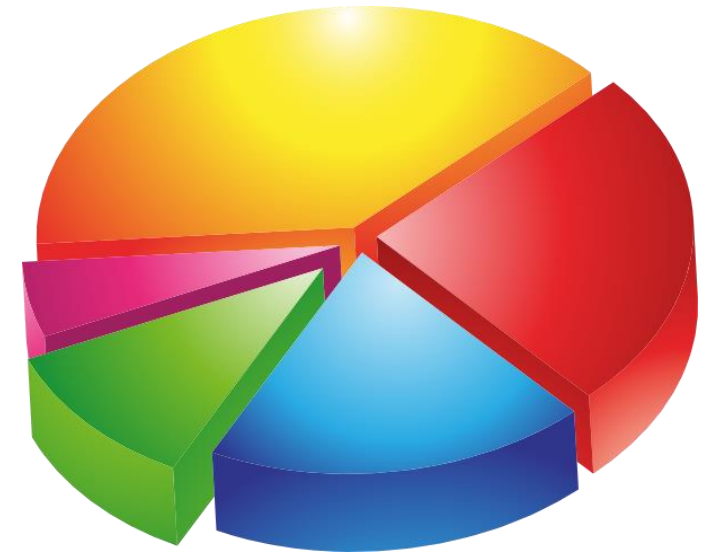
- ✓ Ocean (n=4)
- ✓ Bergen (n=2)
- ✓ Mercer (n=2)
- ✓ Middlesex (n=2)

## Race/Ethnicity

- ✓ White/Non-Hispanic (n=11)
- ✓ White/Hispanic (n=1)
- ✓ Black/Non-Hispanic (n=2)
- ✓ Black/Hispanic (n=1)
- ✓ Prefer not to say (n=1)

## Top Causes

- ✓ MVC (n=7)
- ✓ Assault (n=2)
- ✓ Falls (n=4)





# TBI Fund Update

- ✓ TBI Fund has paid out \$2,378,583.46 for direct and case management services
- ✓ TBI Fund has awarded \$3,032,376.60 in services for FY24
- ✓ Technology Initiation Proposal (TIP) form has been completed and under review of TBI Fund online management system
- ✓ TBI Fund will be hiring 2 more employees

# Open Discussion

11:50 – 12:00



**Next Meeting: October 15, 2024**

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**Homework: TBD**

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