Consumer/Professional Suggestions Regional Meetings 2019

SHIP/MRC

- 2 people mentioned help needed at SHIP to fill out the application. Revise application.
- SHIP services needed faster, not waiting over a year.
- Time to change criteria for SHIP services to cover all ABI.
- SHIP database needed.
- Improve communication between SHIP and consumers.
- SHIP needs better funding.
- Days Services—problem arises when people don't attend for various reasons. Fixed everyday costs don't go away. More flexible model needed.
- People coming to day programs, sometimes need more than 1-1. Not just money, hire a resource coordinator.
- Help with navigating the system.
- State agencies better share information.
- 4 people praised New Start Center but wanted more funding to add new centers in state.
- Telehealth example if unable to fund more New Start programs?
- Club House with 24-hour setting?
- Educate individuals on navigating the system.
- Need robust service delivery system.
- Better employment services from MRC.
- 3 people testified about the gaps in services and wishing for better access to services.
- Any federal money to help states provide better services for people with BI.
- Improve assistive technology.
- Better training for state staff for people with disabilities.
- System of Care---confusion---people don't know how to get from point A to point B.
- Pleased with programs offered at BIA.
- Funds needed for SHIP to help more with mental health issues.

Concussions

- 2 people mentioned Baseline concussion testing.
- Educate teachers on BI and concussions.

Waiver Programs

- Better training for state staff for people with disabilities.
- ABI waiver needs to be changed.

Medical Community

- Individuals in the medical field not educated enough about state services.
- Have medical schools educate students more on BI and ABI.
- In service training for Mass Medical Society.
- Every case worker at discharge should recommend SHIP or MassHealth and give support at this point for filling out the forms. Inform them about BIA.
- Additional education for doctors in the western part of the state on TBI/concussions.
- Provide information materials for patients/families at the ER, doctor's offices etc.
- Education for professionals on ABI/TBI.
- ERs need to distribute information on BI and BIA-MA.
- Berkshire County has a severe shortage of doctors/providers for BI.
- ERs need to distribute information better.
- Doctors needed in Berkshires. Incentives for medical students to move out to western part of state.
- Help doctors better understand the invisible injury.
- Hand-out should be given out—include info on provider resources, what services are available. Train doctors and their staff to talk about services.
- Educate doctors with continuing education forum.
- Misdiagnosis of BI in MA compared with NY.
- Communication needs to be improved between medical community and survivors/families.
- Better information needs to be shared with BI survivor and family members.
- Educate doctors and families better. Make sure people know about BIA support groups.

Elderly

- Focus recommendations for elderly with BI.
- Interagency activities between Elder Affairs---TBI with the aging community. Think outside the box.
- Increase services for people aging with BI.
- Funding needed with the coalition with BI and aging.

Youth/Schools

- More focus on sports related TBIs and TBIs for children.
- Focus recommendations for young kids with BI.
- Better education for schools on BI.
- Employers and schools need more info on BI.

Veterans

• Veterans and coordinated education on BI.

• Veterans with BI need to work better with Veterans Administration for western residents.

Transportation

- 8 speakers mentioned need for better transportation
- Uber/Lyft to help with transportation

Regional Issues

- Medical specialists in brain injury/concussion needed for the southeastern part of MA. Spaulding location in Sandwich needs more doctors.
- Housing problems in various parts of the state.
- Berkshire Medical needs to change protocol for dealing with people with BI.
- Lack of service providers in the western part of the state.
- Baystate support group in Springfield is vital.
- Western hospital did not tell family about BIA.

Opioids and Mental Health

- Skilled professionals needed with background also in mental health, drugs/alcohol and BI.
- Mental health and BI agencies work together. Better understand these communities.
- Better support for cooccurring conditions. DDS and substance abuse.
- Coordination between DDS, MassHeath, MRC and UMass---coordination of staff also the BI world and SUD.
- Jails should ask if one has had a BI/substance abuse.

Cognitive Rehabilitation

• 2 people spoke about cognitive rehabilitation covered by insurance and more facilities/providers offering the service.

Providers

- Better the infrastructure for providers.
- Staff in residential facilities need more training on BI.
- 4 testified about the staffing crisis in nursing homes, facilities.... Wages need to be increased. Need to increase funding rates.
- Amounts need to be adjusted for new residential development. (changes to caps)
- 2 testified about the need more money when new person added to home.
- Not all facilities are used for MA resident's in western part of state.

- Change the 90-day requirement in a nursing home so more people can be eligible for services.
- Peer support in residential homes.
- Rate provisions---problems for nurses and behavioral specialists.
- Occupancy rates.
- Reexamine the ABI waiver for the 90-day requirement in a nursing home.

Miscellaneous

- MassHealth vs. Medicare for survivor.
- Guardianship for adult survivor because refuses to go into residential home.
- 2 comments on 1st responders and need for better education.
- Should fire, police and ER people speak before Commission.
- Help with legal issues surrounding domestic violence/divorce/restraining orders.
- Law school students to help with legal issues in western part of the state.
- Legal assistance for person or family.
- Introduce/promote alternative medicine to aide one in recovery and living after BI.
- Convince insurance to cover alternative medicine.
- Should there be a federal agency to lead states with a different lead agency in the state.
- State card to show one has a BI.
- More support groups in the state.
- Pay care givers
- 4 spoke about the need for more education.
- Help fund BIA-MA more.
- BIA's support groups are awesome, could always use more of them.
- Felt she was part of the tribe once she found BIA.
- Increase public education on BI not just focus on concussions.
- Increase education for caregivers.
- Issue surrounding pensions and collecting early because of a BI. (person couldn't collect social security because never paid into it)
- Fishing fees?
- Disability insurance and coverage for BI.
- Aging parents caring for child with BI. Child is self-sufficient but can't live on own. Residential options?
- Make TBI not the invisible injury.
- Teach people to better advocate for themselves.