

Minutes for TBI Advisory Board Workgroup Meeting

Call to Order

A TBI Advisory Board Workgroup meeting was held on November 6, 2018 at the UAMS Center for Distance Health Adam Rule Training Center. Kim Lamb called the meeting to order at 10:05 a.m.

Attendees

Terri Imus, RN, BSN (Director of Operations, Trauma Telemedicine Coordinator, CDH, UAMS)
 Tina Benton, RN, BSN (Program Director, ANGELS, UAMS; Oversight Director, CDH, UAMS)
 Kim Lamb, MS (Assistant Director of Programs, TBI State Partnership Program, UAMS)
 Daniel Bercher, PhD, NRP (Assistant Director, ATRP, UAMS)
 Kristen Alexander, MPH, MPS (Health Educator, ATRP, UAMS)
 Edward Williams, RN, BSN (Nurse Educator, ATRP, UAMS)
 Amber Watson, MBA (Administrative Coordinator, ATRP, UAMS)
 Sha Anderson, MBA (Executive Director, Arkansas State Independent Living Council)
 Stanley Ellis, Ed.D. (CDH Director of Education, Assistant Professor, UAMS)
 Stacy Gravett, MA, CRC (Vocational Rehab Counselor, Arkansas Rehabilitation Services)
 Sara Hodge, MCD, CCC-SLP, CBIS (Clinical Evaluator, NeuroRestorative Timber Ridge)
 Kelsey Ingle, MS, CCC-SLP, CBIS (Speech Pathologist IV, BHRI)
 Rani Lindberg, MD (Associate Professor, Physiatrist, Physical Medicine & Rehabilitation, UAMS)
 Tom Masseau (Executive Director, Disability Rights Arkansas)
 Miranda Morris, MA (Executive Director, Arkansas Center for Health Improvement)
 Joe Page III, MSCJ (Warden, Arkansas Department of Correction – Tucker Unit, & TBI Survivor)
 Barbara Smith, RN, BSN, CPC (Director of Continuing Medical Education, UAMS, & TBI Survivor)

Welcome & Introductions

Welcomes and introductions were made for the attendees that had not previously attended. Sha Anderson, Dr. Rani Lindberg and Miranda Morris introduced themselves. Dr. Daniel Bercher introduced the new ATRP Nurse Educator, Edward Williams.

Update: Governor's Input

Terri Imus gave an update that word has not yet been received on whether or not the board will be governor appointed or volunteer. Maurice Rigsby, governor liaison for UAMS stated he will follow up with this soon.

Update: Trust Fund

Terri Imus stated that there is a person at UAMS who finds donors so hopefully she will be able to find a donor to help set up a trust fund. Mrs. Imus believes that if a trust fund is established that there will be more people willing to join the cause and help. Kim Lamb requested if anyone knows anyone that will be interested to let her know.

NASHIA Overview

Kim Lamb and Terri Imus recently attended the NASHIA (National Association of State Head Injury Administrators) Conference on September 24-27, 2018 in Des Moines, Iowa. Kim Lamb gave a recap of some important information they learned there and what they can bring back to apply to Arkansas. Presentations at the conference included clinical and educational topics as well as survivor and caregiver stories. Topics included TBI registry, opioid epidemic, program development, policy, etc. The NASHIA Organization tracks federal legislation, proposed rules and regulations and policies related to TBI. Terri Imus will be representing Arkansas on the Policy Committee and Kim Lamb will be representing Arkansas on the Training and Education Committee.

At the conference, Mrs. Lamb and Mrs. Imus were also able to meet with representatives from Administration for Community Living (ACL). They also met with mentor and partner states for each assigned ACL workgroup. One collaborative project is expected of the ACL workgroups in addition to the state grant deliverables. Workgroups will meet once a month except for the Waiver and Trust Fund workgroup as they will meet as needed.

NASHIA/ACL Workgroups

1. Underserved Populations
 - ❖ Mentor states include Oregon and West Virginia
 - ❖ Partner states include Utah, California, Idaho, Minnesota, and Missouri
 - ❖ Will meet monthly
 - ❖ Discussions at the conference included determining underserved populations in each state and important issues such as barriers, case management/resource coordination programs and solutions
 - ❖ Outcome for the workgroup would be a roadmap for the administrators.
2. Advisory Board & Survivor Engagement
 - ❖ Mentor states include Oregon and West Virginia
 - ❖ Partner states include Massachusetts, Alaska, Rhode Island, Georgia, Tennessee, Kentucky, and Minnesota.
 - ❖ Will meet monthly
 - ❖ Discussions at the conference included barriers in each state and strategies to engage survivors and board members
 - ❖ Outcome for the workgroup will be a toolkit for administrators
3. Waivers and Trust Funds
 - ❖ Mentor states include Colorado and Iowa
 - ❖ Partner states include Idaho, Kansas and North Carolina
 - ❖ Will meet as needed
 - ❖ Arkansas was the only state represented at the meeting without a waiver or trust fund
 - ❖ Discussions were made about how each state funded waivers and trust funds such as through fines
 - ❖ Susan Vaughn, policy person from NASHIA, previously worked with the TBI group in Arkansas in 2008 and is on board to help in any way that she can
 - ❖ Outcome for the workgroup would be a documented development process

Developing the Arkansas Plan

Kim Lamb proposed that a formally documented state plan will be developed through the Arkansas TBI Advisory Board Workgroup. Details of the plan within sub-workgroups include state plan development, underserved populations, waiver and financial strategies and a trust fund.

State Plan Development Workgroup

The purpose of the State Plan Development Workgroup is to guide the TBI Advisory Board Workgroup through the development of an Arkansas State Plan by incorporating the work of sub-workgroups.

Tasks of the State Plan Development Workgroup:

- ❖ Benchmark states with existing plans
- ❖ Determine how/what information should be included in the Arkansas Plan
- ❖ Determine how outcomes will be documented

- ❖ Determine how the plan will be shared publicly
- ❖ Other activities identified by the sub-workgroup

Underserved Populations Work Group

The purpose of the Underserved Populations Workgroup is to identify ways to promote and disseminate resources, services, education, and information with the TBI community, especially in the underserved populations identified for the 2018-2021 Arkansas State Plan. Survivor engagement is a key component of this workgroup.

Tasks of the Underserved Populations Workgroup

- ❖ Benchmark states with existing plans
- ❖ Assist with identifying gaps in resources and services in the state
- ❖ Develop ideas/solutions to fill the gaps
- ❖ Assist with developing and implementing four regional activities
- ❖ Other activities identified by the sub-workgroup

Underserved populations for Arkansas 2018-2021 include rural populations, older adults, individuals with substance use disorders, incarcerated or formerly incarcerated individuals, survivors of intimate partner or other forms of violence, caregivers and veterans. Sara Hodge added that she believes an underserved population is anyone over the age of 21 with Medicaid or uninsured. This population may not have access to rehabilitation if they are under Medicaid or are uninsured. Kim Lamb stated she has been working on some assessment tools and hopes to be able to visit the organizations in the community to do interviews and learn more about their programs. The processes have been vetted through IRB.

Waivers and Financial Strategies Workgroup

The purpose of the Waivers and Financial Strategies Workgroup is to benchmark states with existing programs, research new opportunities, recommend ways to develop and implement waiver programs, and identify financial strategies for TBI survivors. Survivor engagement is a key component to this workgroup. Tina Benton stated that one strategy is to create a trust fund with help from donors. This will allow financial help to patients and families in need. Tina Benton stated that there is someone they have met with recently that is interested. The other strategy is to see if there is any possibility to create a waiver. The governmental affairs person is going to approach the governor's office to see if there is any feasibility to that. Both avenues are being explored. Grants are also being looked at as a possibility. Sha Anderson added that there is another path with ABLE (Achieving a Better Life Experience). Tina Benton added she would like to learn more about this path and all avenues are explored.

Tasks of the Waivers and Financial Strategies Workgroup

- ❖ Benchmark states with existing waiver programs
- ❖ Identify ways to increase understanding of service coverage through such entities as Medicaid, Medicare, Money Follows the Person, Social Security, and private insurance
- ❖ Implement activities to increase understanding (workshops, webinars, online, etc.)
- ❖ Consider the role of philanthropy in a waiver program
- ❖ Other activities identified by the sub-workgroup

The purpose of the Trust Fund Workgroup is to benchmark states with existing trust funds, research ways to raise funds, and recommend ways to develop and implement a trust fund in Arkansas. Survivor engagement is a key component of this workgroup. Joe Page added that he hopes that there can be a way to promote

themselves and the initiatives in the right way. He believes with the right promotion people will be willing to help the cause.

Tasks of the Trust Fund Workgroup

- ❖ Benchmark states with existing trust funds
- ❖ Identify areas where funding and support are needed in Arkansas (respite assistance, transportation, lodging, gas, food, education, etc.)
- ❖ Work toward implementing funding sources and opportunities (community fundraisers, Amazon Smiles, Kroger Charity Donations, etc.)
- ❖ Other activities identified by the sub-workgroup

Kim Lamb stated that each group will need an identified leader and requests that if anyone is interested in being a leader of any of these workgroups to let her know. All workgroup efforts will feed into the Arkansas State Plan and will have quarterly meetings to provide updates.

Discussion

An inquiry was made about how many people will be in each workgroup. Terri Imus responded that three to five people would be a good starting point but can be extended depending on how many people with different expertise is needed for that workgroup. Sha Anderson responded that three to five would be a good starting point but to be cautious as to adding too many members as it would impair the function of the workgroup.

Update: Arkansas Trauma Rehabilitation Program (ATRP)

Kim Lamb stated that ATRP Social Media is being used to get information out about programs, events, etc. Mrs. Lamb requested that if anyone has any events or programs they would like to share on the Arkansas Trauma Rehabilitation Facebook page to let her know.

Dr. Daniel Bercher gave an ATRP update. One focus of ATRP is outreach through methods such as reaching out to patients in the TBI registry, connecting with trauma coordinators, the TRIUMPH Call Center, and teleclinics. The annual Arkansas Trauma Rehabilitation Symposium is in the works and is being held on May 2nd and 3rd at the Wyndam Riverfront in North Little Rock. ATRP is also working on Survivor's day which will be held on March 28th or 29th. A research group is also being formed to be able to find research questions, not only academic research but also find out what is going on with the TBI patients in Arkansas. Another avenue being explored is the LoveYourBrain Foundation's yoga program for people with TBI. Blue Nyla Yoga in North Little Rock will be hosting these classes for survivors.

Incorporating Mild TBI into Registry & Follow-Up Process

Terri Imus stated that the trauma registry already reports mild TBI's. She added that she feels like this population is not getting the resources they need and is underserved. The hopes are to incorporate the mild TBI's into the TBI registry to be able to better serve this population. Dr. Rani Lindberg stated that by excluding people with GCS scores above 13 or 14, a large number of people will be excluded that may have deficits. Kelsey Ingle included that a reoccurring problem with mild TBI's is that they are not given a cognitive assessment until they get to rehab. She added that there needs to be some form of cognitive assessment tool for people who come to the ED with head trauma.

Next Steps

Next steps include sign-ups for sub-workgroups and holding sub-workgroup meetings. The next quarterly meeting will be the week of February 4th.

Adjournment

Kim Lamb moved that the meeting be adjourned at 11:30 a.m.