## In January 2019, ACL asked for thoughts and ideas from TBI stakeholders regarding the future contract for the TBI Technical Assistance (TA) Center. ACL received thirteen emails with these recommendations. Below are some of the common themes from these responses.

**Resources and Materials** were some of the most requested needs. Respondents wanted the TA center to create templates, fact sheets, PowerPoints, position/white papers, webinars, and links to resources. Respondents also requested that ACL and the TA provider maintain a space for the storage and sharing of documents including legacy documents. Additionally, stakeholders wanted the TA provider to collect current state information from both grantee and non-grantee states, such as which states have registries, state advisory boards, and TBI waivers

**TA Expertise**: The respondents felt the TA center should employ staff with a high degree of expertise in the TBI field. Stakeholders felt that the TA center should have a national presence, should understand state programs, and be knowledgeable on existing resources.

**Communication:** Respondents felt consistent communication was important to the success of the program i.e., the ability for grantees to collaborate with each other and for ACL to collaborate with outside stakeholders via conference calls and webinars in order to share best practices, research studies, and other hot topics. Respondents requested a website with a space for virtual collaboration on shared initiatives.

**Coordination:** Respondents wanted to see coordination between the TA center, federal and state agencies, and brain injury organizations. Respondents requested that the TA center partner with a variety of other national networks such as the National Association of State Head Injury Administrators, the Centers for Disease Control and Prevention, the National Institute on Disability, Independent Living, and Rehabilitation Research, Substance Abuse and Mental Health Services Administration, Department of Defense, and National Council for Behavioral Health.

**TBI Conference/meeting:** A few of the respondents requested an annual in-person conference hosted by ACL as the preferred way to increase knowledge and network with fellow stakeholders.

**Data/Evaluation:** Some respondents recognized data collection & evaluation for the TBI program was important to measure the impact of the TBI program and that the TA center should be central to that effort.

## These recommendations closely align with the ***2016 As-Is Assessment*** by Coray Gurnitz Consulting, Inc. The key findings shared in the report and listed below are from interviews conducted with TBI stakeholders.

**The roles of ACL’s programmatic staff and the corresponding roles of the TBI TAC require definition.** As the new managers of this program, ACL must determine what level of support they expect to provide to the state grantees, and what corresponding level of support they need from a TA contractor.

**There is a desire for a registry of state resources*.*** As there were only 20 State TBI grantees at the time of the report, information about state TBI capability is limited in the majority of states and territories.

**There is a gap in federal coordination.** ACL can help improve federal coordination by sharing research and best practices and maximizing federal resources through collaboration.

**There is a desire for an annual TBI conference, with an open invitation to all stakeholders.** In-person conferences are a preferred way to increase knowledge and connect with other stakeholders.

**Stakeholders at all levels would like frequent access to information**. It is important to create mechanisms to share updates with the broader TBI community. This applies to project work, research work, and data collection.

## Below are the stakeholder responses. Text has been edited for clarity and to remove all identifying information.

### Email #1:

#### In the early 2000's, the TBI TAC was a very active and available resource for the states. They assigned staff members to be dedicated resources for specific states. The benefit for me with this model is that assigned staff person really got to know your state, its systems and the grant staff very well and this was helpful in informing the suggestions and assistance they provided. I was very comfortable emailing or calling up [our] contact within the TBI TAC and bouncing ideas off her and asking about other state's experiences with various issues.

#### What I think would be helpful, and this isn't news to the folks at ACL or Grant Thornton, but the states really need a way to easily communicate with each other so we don't reinvent the wheel. I was very active on TBI List serve. It was a very helpful tool to keep up with what other states were doing and share information/knowledge we have that might be useful to our funded and unfunded peers. When Grant Thornton took over the contract, that connection ceased and I think that was unfortunate for all parties as we had a lot to offer to both unfunded states as well as the funded states. Remaining active in the National Association of State Head Injury Administrators fortunately offered a mechanism to  fill in some of the gap [our state] experienced in terms of ongoing technical assistance and collaboration via their webinar series, email newsletters and yearly conference.

#### I think collecting and helping to create templates of fact sheets, power points, white/position papers and making those readily available to the states will be helpful. There is so much good work being done around the country, we don't want to duplicate products but want the ability to customize such products to meet our state's needs. I believe all states need to make sure that we create user friendly/person centered tools that speak to all of our audiences e.g. families, individuals with brain injuries as well as our fellow professionals who serve individuals within their systems who are living with brain injury, such as behavioral health, veterans, aging and cognitive disabilities service providers.

#### I strongly believe that the brain injury community cannot just preach to the choir of the sometime insulated brain injury world, we need to bring together our partners across systems to better serve individuals whose brain injuries are not known or not recognized/adequately treated and who didn't receive services via the traditional and recommended route, e.g trauma center to inpatient TBI rehab to outpatient TBI services. The positioning of the TBI Program within ACL offers opportunities for us to collaborate and cross train with our colleagues in aging and disability services as well as those working within the Centers for Independent Living across the country. In the future, perhaps the TBI Technical Assistance Center can use its resources and webinar/virtual meeting platform(s) to bring together entities within ACL as well as those outside ACL, both at the national ( such as SAMHSA, the National Council for Behavioral Health) and at the state level, (such as state brain injury alliances and associations and criminal justice organizations) to share knowledge and resources to better support those impacted by brain injury.

#### Lastly, I understand there has been a great deal of focus on how does the TBI Program conduct program evaluation so that we can quantify and report on best practices and the impact the program has across the country. I am interested in capturing evaluation information beyond the level one evaluation for example we ask training attendees to fill out immediately following a training. I wish we had a way to gauge impact over time. Having done training for 15 years, I know anecdotally training and education makes an impact. For example, one woman attended a TBI Grant sponsored training held almost 15 years ago, last year she attended a TBI training and shared since she first learned about TBI screening from attending that earlier training, she consistently screens all individuals she sees in her community psychotherapy practice and has developed a network of neurologists and psychiatrists who are knowledgeable about brain injury in her region that she can refer people to if they appear to need specific brain injury services. Any assistance in helping us improve our ability to measure the impact of the TBI Grant activities would be very welcome.

#### Thank you for providing us the opportunity to share our experiences and needs re: technical assistance to the state's brain injury programs.

### Email #2:

#### As a current stakeholder, there are a number of ways that [my state] could fully utilize a TBI Technical Assistance and Resource Center (TBI TARC) in order to provide optimal services and supports to those we serve. TBI is a unique disability that creates diverse challenges and the need for specialized services and supports, and should be reflected in a TBI TARC.

#### The greatest need is for a TBI CC to be able to provide consult **from** experts in TBI service delivery and program infrastructure to states who need guidance **on** service delivery and program infrastructure. A TBI TARC must be able to fully understand TBI and know best how those challenges can me met, as well as be well versed on existing resources in order to meet them. There should be a variety of Subject Matter Experts readily available to assist states with a myriad of issues. Similarly, there should be Communities of Practice on a number of topics unique to TBI being facilitated by a TBI TARC so that new trends and issues can be learned, collected and shared.

#### A TBI TARC must also gather information from and provide equal access to information, materials, and other opportunities to states who are both funded and unfunded. How can a TBI TARC provide comprehensive guidance and recommendations on best practices when the resources and needs of unfunded states are unknown? This would also help to measure impact more comprehensively.

#### Documents, webinars, toolkits, and other materials created by states need a virtual home that is easily accessible by all states, and maintained regularly by a TBI TARC who can categorize and market what is collected.

#### A TBI CC should host an annual meeting for grantees, and sponsor unfunded state representatives to attend if possible. This venue would allow all states to share ideas and initiatives in small groups and collectively to maximize the impact of grant activities and Communities of Practice across topics.

#### A TBI TARC could provide ACL with information gleaned collectively in order to impact the larger system through sharing with national partners. They could also partner with other groups and other TBI TARC (such as NASHIA, CDC, NIDILRR, SAMSHA, DoD) in order to assist states and ACL. The TBI TARC could participate in a variety of other national events, conferences, and awareness activities with groups who don’t know TBI to market information and solicit partnerships.

#### If these components were fully realized, state TBI systems of care would benefit, positively impacting the lives of those they serve. Thank you for the opportunity to provide feedback on this important matter.

#### 

### Email #3:

#### I have worked with I believe four technical assistance contractors involved with the TBI State Grant Program. The most effective contractors were organizations who hired individuals with several years of experience understanding traumatic brain injury on a variety of levels. Here are some things to consider.

#### The relationship between the role and responsibility of the Federal Project Officer vs. the TBI TA/Coordinating Center in working with states should be clear.  I’ve seen Federal Project Officers who have retained a lot of responsibility and oversight for the program and I have seen Federal Project Officers who took a more limited role in working with states. This has caused confusion with states and frustration with the contracting entity. For example at one time the Federal project officer maintained ALL progress reports related to states grants and did not share these with the TA entity.  The TA entity was in the dark when certain questions came up. I have not found this to be the case with ACL.

#### 

#### I tend to think there is a difference between “gathering information” from states and putting it on a website or rolling up aggregate responses and playing it back to states. This is different than providing technical assistance to states. Technical assistance is when I’m stuck and I need an entity who has the experience or knows where to look and is willing to do what is necessary to help me and to see my request through to completion. That to me is technical assistance.  I say all of this because it will help states to know if the successful contractor’s role is gathering information as a coordinating entity or TA or both and what to expect.

#### How have past activities benefitted me? [The current TBICC] critiqued an early version of a needs and resource assessment we were putting together. This was very helpful. [The current TBICC] featured in their “spotlight newsletter” state examples. [My state’s] screening efforts were highlighted and I thought this was helpful to my peers.

#### What design components would best help states? There was so much information in the old TBICS system that I did not see in the [grants.gov](http://grants.gov) platform. There was up to 16 year’ worth of information and this was valuable in not reinventing the wheel. ACL has a new platform but it contains no content (or the switch hasn’t been turned on) and it is not functional. Any new web portal takes time but why not operationalize a portion of the site OR let states know what the status is? I don’t know if this is an ACL or [TBICC] responsibility.  At a minimum a moderated list serve for states to be able to interact and ask questions should be operational via this platform.  Fortunately, this is happening via some of the work groups.  I like the work groups even though it can feel like having a added goal in addition to your work plan depending on a state’s level of involvement. I like the Community Snapshot idea much better than fact sheets states had to provide to HRSA/MCH. My concern is will this get done for 24 states between now and the new contract? There are states that are doing exemplary work and this should be highlighted for the benefit of all and used internally.

#### How could the new TBI TA center benefit the larger TBI community?  It depends of the size of the ACL contract budget. I don’t know what the budget currently is but it seems as if they have their hands full just trying to be responsive to the 24 states with grants and nine work groups. I’ve only spoken with the TBICC once since June. When outcomes are achieved and products are developed they most likely will have the stamp of the lead agency. It’s the lead agencies responsibility with help from the TA/coordinating center to benefit the larger TBI community.  If the TA entity is tasked with impacting the entire TBI community…that’s a tall order…. with a very large price tag. Having said this there is no reason why information from a TA center can’t get out to national organizations for them to get out to their members.

#### 

#### Best Way to Measure Impact and Effectiveness of a new TBI center?  Provide clear lines of responsibility and expectations in the contract and then pay the contractor fairly commensurate with the work.  The other way to measure impact is based on state responsiveness to requests for information from the TA entity. If states are not being responsive it may be they are busy but it may also mean they don’t see the value or the TA entity doesn’t know the answer or where to look. We do mostly systems work at the state level although we are now working around the edges ie screening, case management, I&R etc. People with TBI will know if it’s effective if they get what they want and need or if they receive a clear explanation as to why not - within reason of course. Measuring the impact of the system via a TA center has to happen in collaboration with the LSA and others.

#### Other comments/suggestions: Sandra Knutson who was with NORC and lives in Texas was probably the best person to provide TA to states. Sandra had 40 years of experience.

#### Thank you for the opportunity to respond.

### Email #4:

#### I believe the primary purpose of the TAC is to provide guidance and brain injury expertise to state grantees and to ACL. In order to do this, the entity holding the contract must have experience with brain injury services and especially state programs. This expertise is currently lacking. As a result, the current TAC is able to facilitate communication and ideas between states in a friendly and collaborative way but the TAC is not actually able to guide and enhance the state grantee projects. This is particularly concerning for the new grantees who are especially in need of guidance and leadership. It also appears that ACL is lacking an opportunity to partner with an organization with brain injury expertise that can fully assist ACL staff, all of whom are new to the brain injury field, with managing the program, developing effective funding announcements, developing an effective and functional website, facilitating in person meeting opportunities for ACL to meet with grantees, and advocating at the federal level for adequate resources and program authority.

#### The secondary purpose of the TAC, and also very important, is to assist with developing the infrastructure for states to share best practices, participate in on line chats, trainings, collaborative projects, and in person meeting opportunities. This is currently being done at a minimal level via conference calls with established grantee work groups. The availability of shared meeting space where projects can be collaboratively and remotely worked on by states is lacking. Likewise, there is no noticeable leadership or facilitation or guidance from the current TAC. States are operating on their own to meet the federal requirements with few tools other than those they have access to within their own states. Likewise, there have been very few webinars and limited in person meeting opportunities that have actually been organized or supported by the current TAC.

#### ACL has made it clear that the TBI program, while small, needs to have a larger and broader impact and that there is a desire to involve unfunded states as well as to ensure that the work being done by funded states can be shared and expanded nationally. These are important and I believe reachable goals. In order to actually achieve them, the new TAC must have a national presence, brain injury state program expertise, a broad membership of state government brain injury programs as well as other brain injury partners such as professionals and advocates.

#### Thank you for the opportunity to comment.

### 

### Email #5:

#### A few of services helped me

#### 1)DVR helped me a lot when I returned to work

#### 2)TBI fund helped me purchase the hearing aid I needed after developing tinnitus after my accident

#### 3) Because, I am unable to drive I need to  use Access link and though the service is helpful it can be improved.  I don’t know how to make reservations by computer so I need to call and it takes 30-50 minutes of waiting to make a reservation. Sometimes, I need to go somewhere at 9 and need to book a reservation at 630. The 1/2 fare program by njt is helpful, when I need to access that.

### Email #6:

#### How have past activities of the TBI Coordinating Center benefitted you and your affiliated programs?

#### Serve as a resource for various topics such as neuro-behavioral health programs, other states Medicaid state plan information, Employment and Economic Impact Research.

#### Connections with other states TBI contacts and professionals in specific fields of study

#### Brainstorm solutions to challenges and identify resources

#### What design components (e.g., activities, tools, resources) would best help states create and strengthen their systems of services and supports in order to maximize the independence, well-being, and health of people with TBI, their family members, and their support networks?

#### Listing of states TBI programs and current contact information

#### Listing of individuals with specialty knowledge and skills (i.e. SUD and TBI, MH and TBI, employment, working with sister state systems, developing new programs)

#### Links to tools and resources such as OSU TBI ID Method, TBI assessments used for state Medicaid and other programs, online training modules, etc.

#### Listing of historical grant products by topic

#### Listing of current grant projects being worked on by each grantee state

#### The focus of each Disability Rights office as it pertains to their TBI funding.

#### Listing of states that have TBI registries or other similar tracking of TBI’s for the state, including contact information.

#### Listing of states with TBI Advisory Boards/Councils.

#### Have readily accessible, current (as possible) TBI data from CDC and other sources.

#### Current and pending federal legislation that affects/could affect the TBI community.

#### How could the new TBI technical assistance and resource center best benefit the larger TBI community?

#### Have a working knowledge and understanding of TBI. Most all TA centers in the past have started from scratch trying to understand TBI and what resources exist for this population.

#### Have a working knowledge of state and federal systems, how they interact, how they complement one another, etc.

#### Awareness of general resources available/ability to access information/make referrals

#### Have a designated place on website to highlight “best practices”, “promising practices” “whats new”, research studies and other hot topic items.

#### What is the best way to measure the impact and effectiveness of the new TBI technical assistance and resource center both on state systems and on people living with TBI?

#### Surveys to states that rate TA center performance---meeting needs, accessibility, helpfulness, etc.

#### Level of accessibility (i.e. online information-website, email, phone)

#### Demonstrated knowledge of the disability and resources.

#### Report from TA Center describing projects/issues they have assisted with, method of assistance and outcome.

### Email 7:

#### To whom it may concern:

#### On behalf of [my organization] and, most importantly, people impacted by brain injury, I am submitting thoughts and ideas relative to public input on the next TBI Technical Assistance and Resource Center.

#### Specific thoughts and ideas are listed within Addendum One below. It is my intent that these items listed will provide some idea as to what the brain injury community needs. To that end, perhaps processes can ultimately be created that can provide people with brain injury with the technical information and resources they may need to address the needs listed below.

#### If you need anything further from me to ensure that the Administration for Community Living effectively reviews these thoughts and ideas, please contact me.

#### Thank you for this opportunity and consideration.

#### **ADDENDUM ONE**

#### **Advocacy**: People with brain injury need advocacy services that empower themselves and/or their caregivers to ensure quality of care provided is of high standard. People with brain injury need to understand their rights and to learn to ensure these rights are honored.

#### **Exercise**: People with brain injury need physical exercise and socialization geared specifically to the brain injury population.

#### **Emergency Alert System**: People with brain injury need to learn how to register for and utilize emergency alerts that can be transmitted through computer, smartphone, other medical alert systems etc.

#### **Nutrition**: People with brain can benefit from classes on how to cook; use appliances; food preparation (chopping, slicing, dicing, recipe instructions, kitchen safety with knives, stove), preservation, and discarding when food is spoiled; nutrition education; weight maintenance. People with brain injury may need food delivery services and subsidies to pay for food delivery.

#### **Financial/Legal**: People with brain injury may need navigators to assist with proper completion of certain types of documents (legal paperwork, financial documents, insurance, tax return preparation, other applications and papers).  **Please note**: Meeting deadlines is crucial for submitting certain documents. Some people with brain injury need assistance in this regard and information to help them access such assistance.

#### **Independent living**: Education programs/services to help maintain independence to live is crucial for those who live alone and/or have no family; especial if they do not qualify for group home services, etc.

#### **Socialization**: Social events involving other TBI survivors and caregivers are important so that experiences, information, and bonding can occur; can empower us and improve quality of life for people impacted by brain injury. Support structures and/or community sponsored events can help alleviate depression many people with brain injury have. Socialization can give a sense of worth and of belonging. Accessing information in this regard can be quite helpful to people with brain injury.

#### **Support groups**: Support groups should be made available to every person impacted by brain injury. Reliable support structures are ones that will respond to individual concerns effectively and efficiently.

#### **Transportation**: One of the biggest challenges people with brain injury reference is lack of transportation. Transportation is an integral part of living fully in the community; inclusive of accessing medical care and surgery and attending religious services. Some people with brain injury utilize non-medical transportation. Although useful, there are limitation on how far non-emergency medical transportation services will transport someone with brain injury. In other circumstances, some people with brain injury accompanied by walking challenges may need to walk a certain distance to access transportation services. Transportation to attend religious services

#### **Therapies**: Some people with brain injury are in need of various therapies (cognitive, speech, physical, emotional); and may need therapy to assist them with Post Traumatic Stress Disorder manifested as a result of sustaining a brain injury. Some in the brain injury community have found benefit in different therapies such as massage, homeopathic, and/or spiritual therapies. Access to these therapies should be considered as means toward supporting people with brain injury in the community.

#### **Medication**: Improper use of medicines can attribute to devastating results including, but not limited to, opioid abuse. People with brain injury are not immune from such abuse; which may be the result of using medicines in an improper way. As many people with brain injury have cognitive challenges, said challenges can result in abuse of medicine. Therefore it is imperative that special consideration be applied toward educating people with brain injury on the proper use of taking medicine and side effects of medicine. Also, it may be a good idea to focus on decreasing reliance on medicines to maximize recovery from brain injury (and prevent possible addiction to opioids).

#### **Medical equipment**: Some people with brain injury have expressed needing access to equipment that could be useful to them (thus suggesting accessibility to equipment is a challenge).

#### **Job assistance**: Support is needed for people with brain injury who have a job and no longer qualify for job assistance because they are employed. Some people with brain injury may get taken advantage of in the workplace. As such, they need to be empowered to address perceived abuse whether it be from coworkers or customers.

#### **Housing**: Some people with brain injury need assistance with relocating to a disability accessible home. They may also need continued support to use certain housing-related programs (ex: housing, rental Assistance, LIHEAP) so as to remain in the community. As such, assistance with effectively completing renewal applications and open enrollment procedures may be necessary so that the person with brain injury can continue using the programs.

#### **Positive motivation**: Inspirational and motivational programs aimed to help people impacted by brain injury remain positive can always help. Family support education/training focused on proper interaction with person with brain injury can also be helpful. Some people with brain injury may benefit from such awareness as some people may interact with the person with brain injury in such a way that makes the person with brain injury feel like a burden. Programs to facilitative positive self-image as a person with brain injury and connectedness to others can always help.

#### **Long-term planning**: Information with long term planning – retirement, housing, goal setting, etc. is a need.

#### **Support/guide/service animals**: People with brain injury may need information regarding how to secure and utilize a service animal.

#### **Voting**: Voting assistance-related information ex: assistance with understanding referendum question, transportation to and from polling place is needed by some people with brain injury.

#### **Epilepsy**: Information related to effectively addressing a situation in which a person with brain injury and epilepsy may want to be made available to public employees; particularly those in the public school system.

### Email 8:

#### Thank you for the opportunity to submit comments, thoughts, and ideas about the TBI technical assistance and resource center. It would be helpful if the Technical Assistance and Resource Center is a resource for grantees and non-grantee entities, equally, and could provide the following:

#### Expertise:

#### There are a variety of settings and types of services and supports, that are necessary to address brain injury across the life-span (acute care, skill building, support networks, etc.) – access to professionals who have this information from basic to advanced, from clinical to practical, systems to individuals, and across settings and age groups, as well as survivors and families, is needed. Access to these groups of people for training, consultation, products and information and guidance would be useful.

#### Some areas may include: Young children; school aged children – in school settings (this is an area that has not been focused on, nationally); post-secondary opportunities; juvenile and criminal justice settings; transition to employment; employment; mental health; life skill building; navigation of systems (Medicaid, school systems/special education, home and community based services, mental health, etc.); older adults; Resources and Best Practices:

#### Products, toolkits, and guidance documents

#### Forums for sharing best practices and networking (listserv, directories of state level contacts and providers; searchable database for resources/best practices with snapshots of content, how to evaluate programs/services, grant specific activities; etc.); Fund raising opportunities and resources

#### Collaborative partnerships – to share and create new resources (state government systems; other disability service providers, providers, etc.). Data: the ability to be responsive to the needs of the field – for example:

#### Statistics and trends

#### Fact sheets

#### Policy materials

### Email 9:

#### Here are few of my thoughts and ideas about the new contract for the TBI technical assistance center.

#### Generally I think that it would be more beneficial to have a broader out reach to the TBI community beyond grantees.  My state does have some infrastructure for supporting people with brain injuries including a grant, and advisory board, and a BI Waiver. While I do think that it is certainly important to provide technical assistance to grantees and ensure that these programs have access to best practices and current research so that the grant funded projects are successful, I think we missing opportunities to support states that may have very little infrastructure to even apply for grants.  I think it would beneficial to do more outreach to Brain Injury Associations and Brain Injury Alliances especially in states that do not have a grant and/or have very little infrastructure to offer assistance.  I think it would good idea to more closely connect TBI advisory boards with the TBI Coordinating Center so that they can get assistance with information about promising practices from other states that address identified areas of need.  It may be worth considering having the TBI Coordinating Center host and facilitate discussions around particular topics that they see as themes in the requests for assistance that are coming in.  This may already be happening and I just don’t know about it.

#### When evaluating proposals, that there should be significant weight given to those whose staff have extensive experience working with the BI community. I think this would help to build trust among state and community partners.

#### Please let me know if you have any questions about my comments, or if I can be of any further assistance in the RFI planning process.

### Email 10:

#### How have past activities of the TBI Coordinating Center benefitted you and your affiliated programs?

#### Prior to this current grant cycle we have not used the coordinating center. To be honest, we have mostly used connections that we have established. This is largely because I did not feel that the coordinating center had a grasp on state government and, when they began, they had limited understanding of brain injury. Prior entities that have held this contract offered a comprehensive listserv which I did use to ask questions of other states and I felt that was helpful. Additionally, in the past, having a data base of resources was somewhat helpful but these data bases have always been a challenge to navigate. With our current grant we are working more closely with the coordinating center to develop the core competencies for training etc.

#### What design components (e.g., activities, tools, resources) would best help states create and strengthen their systems of services and supports in order to maximize the independence, well-being, and health of people with TBI, their family members, and their support networks?

#### I think it is critical to have an entity in this role that has a solid understanding of state government and the unique opportunities and challenges that this environment offers. I think it is also essential that the entity have an in-depth understanding of brain injury. That all said, I feel the coordinating center would play a critical role with states. Primarily I think the coordinating center should have their pulse on what states are doing in brain injury to help link states seeking support with states who have advanced experience. The center should be the clearing house for best practices, tools, documents that states can access and not re-create the wheel in their own states. The coordinating center should be able to provide individualized support to states.

#### How could the new TBI technical assistance and resource center best benefit the larger TBI community?

#### Through helping individual states achieve sound infrastructures to support individuals states, the coordinating center will strengthen the larger TBI community.

#### What is the best way to measure the impact and effectiveness of the new TBI technical assistance and resource center both on state systems and on people living with TBI?

#### If the coordinating center is effective this should be measurable in the number of states that have infrastructures in place to effectively support individuals with brain injury across state and private systems. Additionally, states themselves should be able to articulate the support that the center provided to them and their satisfaction with this support.

### Email 11:

#### Thank you for the opportunity to provide input on the next Traumatic Brain Injury Technical Assistance and Resource Center (TBI TARC) employees who work to create systems of support and care for individuals living with brain injury, and their families.

#### **I. Forums for Sharing Best Practices**

#### One of the most common [requests] was the desire for the TARC to create forums for states and stakeholders to learn from one another. In addition to the current ACL – coordinated Stakeholder Day, the TARC would serve its members by hosting some or all of the following:

#### • Routine networking opportunities

#### • Listserv to facilitate communication between state programs

#### • Directory of state contacts and service providers

#### • Database of state programs and resources

#### • Access to comprehensive summaries (“snapshots”) of all state programs

#### • Access to replicable best practices

#### The TARC should collaborate with stakeholder groups to ensure a lack of duplication and maximization of resources.

#### **II. Access to Expertise**

#### [Stakeholders] also commonly highlighted the need for access to TBI-specific experts, both at the TARC and across the nation. Creating systems of care for individuals with TBI is different than other disabilities due to the varied nature of brain injury and high likelihood of co-occurring conditions. Technical assistance by the TARC should be provided by individuals with an understanding of both a basic clinical understanding of TBI but also knowledge of state government systems development and resource facilitation. Outside of the TARC employees, [stakeholders] would like opportunities for connection with experts across the country that specialize in various aspects of TBI (vocational rehabilitation, behavioral health, etc.). A directory of such national experts was also suggested.

#### **III. Access to Data and Resources**

#### In addition to access to people, [stakeholders] request access to national data, resources and literature. Respondents would like the TARC to provide informational webinars and products like fact sheets and toolkits that educate stakeholders on a variety of TBI-related topics. Training packages and policy materials were also referenced, as well as resources on systems development and federal programs like Medicaid. Some believe the TARC should be a “data hub” allowing stakeholders access to national data and evidence-based practices and trends.

#### **IV. Impact Evaluation**

#### Most reported the challenge of identifying appropriate impact metrics due to the “nascent” and “varied” state of the field. However, some ideas include:

#### Development of tools

#### Programmatic and policy development within states

#### Creation of a national roadmap with state goals specific to each state

#### Improvement of access to services by individuals with TBI and their families

#### Survey of users as to utility and quality of services received

#### TARC report on utilization data and outcomes

#### We greatly appreciate your attention to our members’ thoughts related to this important federal resource.

### Email 12:

#### How have past activities of the TBI Coordinating Center benefitted you and your affiliated programs?

#### Previous TA Contractors managed a very interactive listserve/collaboration space that was very valuable and real-time.

#### This TA Contractor has done specific research for us and reached out to other grantees on topic specific stuff (BRFSS Questions, Council agendas, family ombudsman job descriptions).

#### NASHIA developed the Guide to State Government Brain Injury: Policies, Funding, and Services, 2005. That was extremely useful and we’d encourage the new TBICC to be familiar with that document.

#### TBICC needs to find a way to be sure that funded states know what was happening on the ground in other states. We know the other states, so if we know what they are doing, we can collaborate.

#### TBICC should also serve more than just state grantees. The state Brain Injury Associations and Alliances are a wealth of information/expertise.

#### TBICC should be familiar with government and the limitations therein (firewalls, contracts).

#### What design components (e.g., activities, tools, resources) would best help states create and strengthen their systems of services and supports in order to maximize the independence, well-being, and health of people with TBI, their family members, and their support networks? Should develop comparable state profiles. That will facilitate collobaration. Knowing what other states have created is invaluable.

#### How could the new TBI technical assistance and resource center best benefit the larger TBI community?

#### Advance relationships with state contractors and other critical partners.

#### We are looking for staff who understands state government and how we work.

#### TA Center needs to communicate with us regularly, about what “we” are doing.

#### Previous centers did excellent job of compiling state data into national products and disseminating it.

### Email 13:

#### 1. How have past activities of the TBI Coordinating Center benefitted you and your affiliated programs?

#### 1. Full response redacted

#### 2. What design components would best help states create and strengthen their systems of services and supports in order to maximize the independence, well-being, and health of people with TBI, their family members, and their support networks?

#### Thoughts and Ideas 2:

#### Develop a partnership/collaboration with SILC/CIL for strategizing how to enhance or develop a partnership/collaboration with SILCs and provide technical assistance with developing goals/objectives for state plans for independent living (SPIL).

#### Develop a partnership/collaboration with CILs and provide extensive training program to enhance CIL staff skill set for maximizing the independence, well-being, and health of people living with TBI, their family members, and their support networks.

#### 3. How could the new TBI technical assistance and resource center best benefit the larger TBI community?

#### Thoughts and Ideas 3:

#### Develop a partnership/collaboration with SILCs and provide technical assistance with developing goals/objectives for state plans for independent living (SPIL).

#### Develop partnerships/collaboration with CILs and provide extensive training program to enhance CIL staff skill set for maximizing the independence, well-being, and health of people living with TBI, their family members, and their support networks.

#### 4. What is the best way to measure the impact and effectiveness of the new TBI technical assistance and resource center both on state systems and on people living with TBI?

#### Thoughts and Ideas 4: By collaborating with SILCs and CILs the new TBI technical assistance and resource center would have access to SPIL implementation, monitoring, and evaluation data.

#### By collaborating with CILs the new TBI technical assistance and resource center would have access to CIL 704 statistical data that may demonstrate increased services to individuals living with TBI, their family, and their support networks.

#### We recommend developing and funding opportunities for research proposals utilizing centers for independent living and/or institutes for disability research.