

Expanding TBI Awareness Manual

**Traumatic Brain Injury Awareness Program:
Serving Veterans and People with Brain Injury**

Central Coast Center for Independent Living



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Expanding TBI Awareness Manual

Our Vision

Our vision is to promote the independence of people and veterans living with Traumatic Brain Injury (TBI) by building awareness, educating and providing collaborative opportunities throughout California. This handbook covers best practices and components of providing services and outreach to people with a traumatic brain injury throughout California.

Preface

This manual will guide you through the process we used to increase capacity throughout California for independent living centers (ILC) to serve people who have had a Traumatic Brain Injury (TBI). Our goal is to provide ideas and tools that can be tailored to provide services and outreach in your community.

Acknowledgements

We would like to thank our partners who collaborated on this project including: Elsa Quezada, CCCIL's Executive Director, for her leadership and steadfast support; CCCIL's Brain Injury team led by Jennifer Ramirez, Olivia Quezada and all of the CCCIL staff; Tony Sauer, Director of the California Department of Rehabilitation (DOR), and the DOR team including, Megan Juring, Ana Acton, Joanne Lavoie, Dan Clark and Michelle Davis, who worked on overseeing this grant, providing technical assistance, and helped keep this program up and going after the grant ended.

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Bay area ILC Executive Directors: Sarah Triano of Silicon Valley ILC; Eli Gelardin Marin CIL; Paula McElwee former Interim Director CID in San Mateo, and their staff who were instrumental in coordinating various aspects of this project including asset mapping.

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We also appreciate the assistance of Lynda Eaton and all of our webinar speakers; the California Academy of Family Physicians, members of the Statewide TBI Coalition and all of the hundreds of people who helped support our success.

Traumatic Brain Injury in California

What is TBI?

Traumatic Brain Injury (TBI) TBI is caused by an external physical force (such as a blow, bump or jolt) resulting in open or closed head injury. It is estimated that over 1.7 million people sustain a TBI annually in the United States.¹ TBI can cause a range of impairments in motor-sensory, communication, cognitive and behavioral functions depending on the severity of the injury.

Common ways to sustain a TBI

Falls and car accidents are the leading causes of TBI and result in the greatest number of TBI- related emergency department visits.² Sports injuries (football, skiing, etc...) can also result in a TBI. Children under the age of four, older adolescents aged fifteen to nineteen years and adults over the age of sixty-five are most likely to sustain a TBI.³ About 75% of TBIs that occur each year are concussions or other forms of mild traumatic brain injury (MTBI).⁴

Symptoms associated with TBI

Depending on the extent of the damage to the brain, symptoms of a TBI can be mild, moderate or severe. AMTBI can cause “loss of consciousness for a few seconds or minutes, headaches, confusion, lightheadedness, dizziness, blurred vision or tired eyes, ringing in the ears, fatigue, a change in sleep patterns, behavioral or mood changes, and trouble with memory, concentration, attention, or thinking”.⁵

¹ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. *Get the Stats on Traumatic Brain Injury in the United States.*

² U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. *Get the Stats on Traumatic Brain Injury in the United States.*

³ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. *Get the Stats on Traumatic Brain Injury in the United States.*

⁴ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. *Get the Stats on Traumatic Brain Injury in the United States.*

⁵ National Institute of Health, National Institute of Neurological Disorders and Stroke. *Traumatic Brain Injury Information Page.*

Common Symptoms Associated with TBI

Cognitive Effects

- Attention/Concentration
- Processing Speed and Capacity
- Memory
- Planning
- Problem-solving
- Anticipating
- Completing task
- Organizational Skills

Physical Effects

- Fatigue
- Headaches
- Coordination
- Balance
- Balance problems
- Poor fine-motor coordination
- One-sided limb weakness
- Reduced motor speed
- Spatial disorientation

Sensory Effects

- Hearing loss
 - Tinnitus
 - Audio Processing
- Visual system changes
 - Double vision
 - Loss of visual field
 - Visual Processing
- Hypersensitivity to all sensory input
- Loss of smell/taste
- Numbness

Emotional / Behavioral Effects

- Easily Overwhelmed
- Impulsiveness
- Socially-inappropriate comments or actions
- Lack of awareness of deficits
- Communication Skills
- Difficulty in controlling emotions/ Emotional outbursts
 - (crying, laughing, anger, etc,)

A Diagnosis of Traumatic Brain Injury

A TBI diagnosis can result in a variety of outcomes depending upon the location and severity of the injury as well as the age and general health of the individual who sustained the TBI. While the lives of people who have sustained a moderate to severe TBI (as well as the lives of their families) can be dramatically affected by the injury, there are many effective and successful programs available in the areas of rehabilitation, treatment and assistance with daily life.

About the Central Coast Center for Independent Living

The California Traumatic Brain Injury Awareness Program is housed in Central Coast Center for Independent Living (CCCIL) which serves the Santa Cruz, Monterey and San Benito tri-county area.

Twenty Nine Independent Living Centers in California

CCCIL is one of 29 Independent Living Centers (ILCs) in California. Similar to the other ILCs, CCCIL's mission is to promote the independence of people with disabilities by supporting their equal and full participation in community life. We adhered to the Independent Living (IL) philosophy of focusing on consumer driven projects.

People who have sustained a TBI have been identified as an underserved/under-represented group by the State Independent Living Council (SILC). ILCs throughout the state aim to serve people with TBI by providing services to help in their everyday life. The California Foundation for Independent Living Centers (CFILC) is a statewide, non-profit trade organization made up of 25 ILCs. To find out more about CFILC, or to find a local ILC in your community, please visit www.cfilc.org.

Seven TBI Service Sites

In 1988, AB 1492 provided funding to create TBI Service Sites under the seat belt fund. CCCIL is one of these TBI Service Sites in California. Prior to 2009, the seven California TBI Service Sites (TBISCA organizations) were under the jurisdiction of the Independent Living Section of the California Department of Mental Health. This was changed when AB 398 was signed into law, putting these sites under Department of Rehabilitation (DOR). Now both ILCs and TBI Service Sites are housed under the California Department of Rehabilitation. To find out more about these TBI Service Sites go to www.tbisca.org.

One focus of this grant was to build collaboration between DOR, ILC and TBI Service Sites. Through this project, we developed a model for ILCs, DOR and community organizations to bridge the gap to provide appropriate, accessible services to the TBI community throughout California.

Serving veterans and connecting them with Independent Living Centers was another key component of this TBI Project. The project also included training on how to work with veterans and emphasized collaborating with veteran organizations.

Increasing Statewide Capacity to Serve Consumers with TBI

Recognizing the need to expand services for consumers with TBI and veterans with disabilities, CCCIL applied for and received a two year grant funded through the American Recovery and Reinvestment Act (ARRA, also known as the Stimulus Package) to build capacity for DOR, ILC's, TBI Service Sites, veterans organizations and other community partners to better serve the needs of consumers with TBI.

CCCIL began by assessing needs from the perspective of service providers, consumers and their caretakers. We also formulated two advisory committees of consumers to gain valuable insight on the needs for receiving informed, quality services for consumers. One advisory committee served veterans with TBI the other served civilians.

The feedback from the asset mapping survey and advisory committees were instrumental in formulating the work performed throughout the project including: identifying topics and speakers for webinars, giving direction for public policy work, gaining media visibility and creating TBI outreach materials and useful content for the program website, www.catbi.org.

Asset Mapping

Asset mapping is a tool that was created to determine the strengths and weaknesses in different communities for serving people with TBI. We developed an asset mapping data collection tool by researching and analyzing other mapping projects and utilizing some of the surveys from these tools to create new, tailored questions on what is known about the specific needs of people with TBI. This original tool was used internally at CCCIL by researching community resources and utilizing staff experience and knowledge.

Two Bay Area ILCs requested that we facilitate a meeting with community partners for the asset mapping project. If the ILC served multiple counties, we gathered information from one county in the ILCs service. An outreach leaflet was created for the ILCs to distribute to community partners.

Asset Mapping: Marin Center for Independent Living

The first collaborative meetings took place at the Marin Center for Independent Living (CIL). The meeting included nine local participants and key staff from the Marin CIL as well as community partners and a consumer with TBI. This meeting was informative, bringing together a

dynamic collaborative of agency service providers and a TBI consumer working toward gathering the same information. The meeting was productive and so many ideas were shared, it was often challenging to stay on task of completing the survey. The information gathered was correlated and returned to participants along with a full audio tape of the meeting.

Lessons Learned:

One of the lessons learned was that in a smaller community, such as Marin County, there is quite a bit of crossover with the same service providers covering a number of categories. If this holds true in larger population areas, it may be possible to combine some of the categories.

Asset Mapping: Silicon Valley Independent Living Center

The second asset mapping meeting took place at the Silicon Valley Independent Living Center (SVILC) in San Jose. The online reference guide for services available to people with TBI called Traumatic Brain Injury Resource Directory (TBIRD) provided a great deal of information for both Silicon Valley programs and statewide programs. The information was extensively researched prior to this meeting, which resulted in streamlining many categories from the SVILC survey because service provider information was already available. While it did not address all of the accessibility issues of the survey, reviewing this in depth would be redundant and not help to keep participants engaged.

Eighteen people participated at the SVILC town hall meeting ranging from consumers with TBI, service providers and a representative from the Palo Alto Veterans Affairs Hospital, which has one of the five veteran poly-trauma units in the country. Other agency participants included representatives from Services for Brain Injury (SBI Cares), the California Department of Rehabilitation, the City of Sunnyvale and Parents Helping Parents. The Santa Clara Valley Medical Center has a unit that also is geared toward people with TBI. This area is a hub of services for people with TBI. The VA perspective was a necessary component for bridging the gap of providing services to veterans.

At this one hour meeting we had speakers from SBI Cares and Santa Clara Valley Medical Center discuss two specific programs: the Bay Area Brain Injury Task Force (BABIT) and TBIRD, respectively. We then discussed five of the survey areas that were not well documented in the TBIRD information. Discussions of these five areas lead to a spirited conversation about housing.

Lessons Learned:

The questionnaire includes 40 questions and obtains a great deal of information; however, is too lengthy- especially for the format of a meeting with multiple service providers and consumers present. The group meeting process is more productive than having one person from the organization gather data from various sources. It leads to a dialogue and connections, which later promoted strategies for coordinating and expanding services for people with TBI.

Asset Mapping: Center for Independence of Individuals with Disabilities, San Mateo

The third meeting with the Center for Independence of Individuals with Disabilities (CID) in San Mateo had 17 staff members participating. During this meeting, we shared information about TBI and discussed the data collection process. The CID Executive Director requested that staff complete the part of the questionnaire they were familiar with and suggested that they focus on direct services and information relevant to overlapping consumer populations.

Lessons Learned:

The executive director suggested that they use the data collection tool as an opportunity to assess the various services available to their consumers across disabilities.

For more information on **Asset Mapping**, these documents can be downloaded from the thumb drive provided with this report:

➤ **Asset mapping**

- ⇒ [Data Collection Tool](#)
- ⇒ [Sample Excel Analysis](#)
- ⇒ [Data Analysis](#)

Systems Change Advocates Survey

A survey of ILC systems change advocates was introduced separately in Northern and Southern California. They explored whether to include issues regarding TBI in their local systems change plans. This resulted in a wide range of feedback regarding underserved groups such as people with TBI being included into the site plan. The completed surveys were tabulated.

Supporting documents relating to these **systems change surveys** are available on the thumb drive provided with this report:

➤ **Systems Change Survey**

- ⇒ [Survey Tool](#)
- ⇒ [Analysis Tool](#)
- ⇒ [Survey Report](#)

TBISCA Outreach Survey

There are seven Traumatic Brain Injury Services of California (TBISCA) sites in California and each was given survey questions. The sites provided information on outreach efforts for a six month period from October 2009 through March 2010. All seven sites responded to the survey.

There was a follow up survey and report covering the same six month period from October 2010 through March 2011. The tools and results are available below.

For **surveys results and developed tools**, these documents are available for download on the thumb drive provided with this report:

➤ **TBISCA Outreach Survey**

- ⇒ [Survey and Instructions](#)
- ⇒ [Survey Report](#)

Independent Living Services for TBI Consumer Survey

A survey was sent to the 29 centers for independent living in California. This was combined with a pre-webinar survey which went out prior to the first webinars. It is intended to address the delivery of services for consumers with TBI. The intent is to determine the level of preparedness ILCs have to serve consumers with TBI, if there has been a change in the numbers of consumers with TBI that they serve and relevant issues around serving people with a TBI. According to the CILR report provided by Department of Rehabilitation, there has been an overall increase in the number of consumers with TBI in California that were served by ILCs between Fiscal Year ending September 30, 2009 and the year ending September 30, 2010.

For examples of the **survey and cover letter** we used, download these documents (located on the thumb drive provided with this report):

➤ ***IL Services for TBI***

⇒ [Cover Letter](#)

⇒ [Survey Tool](#)

Traumatic Brain Injury Advisory Committees

The goal of hosting Advisory Committees was to create opportunities for individuals with TBI to participate in the process of identifying barriers to TBI services and expanding, coordinating and improving TBI services. Our goal was to create two TBI Advisory committees, a Civilian and Veteran committee, as part of our program. All participants are people with TBI and include eight participants in each committee.

The Committees identified barriers facing people with TBI and the best possible solutions to overcoming those barriers. They also provided feedback on the marketing and public policy activities as well as how to address ILCs and other community organizations effectively serving veterans' with TBI.

The veterans TBI Advisory Committee provided valuable input and feedback on increasing awareness of TBI and educating legislators on the issues that are facing veterans with TBI. This committee gave guidance on how to assist and inform ILCs and other community organizations, so that they can more effectively serve veterans with TBI. The Committee also provided suggestions on media messaging, public policy issues and determined the methods used to address these issues.

Advisory Committee Recruitment

Recruitment took place for consumers with TBI in Monterey, San Benito and Santa Cruz Counties. The Civilian Advisory Committee first met on July 27, 2010 and the Veterans Advisory Committee had their first meeting on July 29, 2010. These committees met once every two months for one year, until July, 2011. These advisory committees followed the independent living philosophy of including consumers in the decision making process.

For more information on the **Advisory Committees**, these documents are available and located on the thumb drive provided with this report:

➤ TBI Advisory Committee

- ⇒ [Application Rating Form](#)
- ⇒ [Application Veteran](#)
- ⇒ [Application Civilian](#)
- ⇒ [Interview questions](#)
- ⇒ [Evaluation](#)

Raising Awareness about Traumatic Brain Injury

Disability Capitol Action Day (DCAD)

As part of our efforts to increase awareness of brain injury in 2011, CCCIL brought consumers, including veterans living with a brain injury to the Disability Capitol Action Day (DCAD). One of the veterans arranged to have an outreach booth for Disabled American Veterans (DAV) at this event. Most of the participants were members of the TBI Advisory Committees. These consumers chose to visit their legislators in order to tell their stories and increase understanding of what is like to live with a brain injury. The veterans also met with legislators to give a firsthand account of their lives and barriers that they face.

Webinars: Improving Service Coordination for People with TBI

A total of eleven webinars took place with the first nine regionally focused on Northern, Central and Southern California. The subject of the two additional TBI webinars focused on Youth and Assistive Technology (AT).

To prepare for the webinars, a meeting was held at the Center for Independent Living Centers (CFILC) in Sacramento. A series of questions were answered and a demonstration of the Elluminate platform was demonstrated. Elluminate has a number of features that we were able to utilize during the webinars including the ability of participants to change the format for accessibility, raise their hands for questions and allow presenters to poll the audience when discussing a specific issue.

A pre-webinar and post-webinar survey were conducted to assess the amount of benefit the attendees received from the webinars and to determine if the content was at the appropriate level for this audience.

The first three webinars included a presentation from Lynda Eaton from Mercy's Home and Community Program. Ms. Eaton provided information

on TBI and discussed the causes and effects of TBI. She then spoke on strategies for providing accessible services to consumers and accommodations for people with TBI. During each webinar, Ms. Eaton presented region-specific service needs in Northern California, resources available for integrated services as well as barriers and unmet needs from a service provider perspective.

A regional perspective for Central California was presented by Jenny Oshiro of the Janet Pomeroy Center and Claudia Ellano, Executive Director of St. Jude's Brain Injury Network presented for Southern California. Consumers from each region provided their perspective on the barriers and resources available for TBI consumers and their families. Robert Cline was the Northern California consumer; Tim McKay provided the Central California consumer perspective. James Marshall was the Southern California consumer on the webinar.

Lessons Learned:

Doing a full presentation on aspects of our program including the webinars at the CFILC statewide meeting provided increased interest in having their staff attend. It would have been helpful to pass around a clipboard and find out the proper point of contact. In an effort to create as much participation as possible it is necessary to provide multiple pre-event notifications. While the save-the-date was sent out a couple of months in advance, more detailed information was only available two weeks prior to the webinar-which was not enough time. We also found that we were unable to track how many people were sharing a site and if outside agencies were invited to their site.

Veteran Culture and Veterans Affairs Service Coordination Webinar

Ted Puntillo, Deputy Secretary of the California Department of Veteran Affairs was instrumental in gaining access to speakers for the Veteran Webinars.

The topic of veteran culture was the first part of the presentation done by Brock McNabb and Jeremiah Ridgeway of Capitola Veterans Affairs, Their presentation highlighted ways of increasing veteran's comfort level in working with service providers. This included commonly used acronyms such as RPG (rocket propelled grenade) MOS (what the veteran did while in the service), OIF, OEF and OND (Operation Iraqi Freedom, Operation Enduring Freedom and Operation New Dawn). The presentation also included the Mobile Veteran Clinic.

Dr. Cynthia Boyd of the Defense Veteran Brain Injury Center spoke on "What is Unique about Serving Veterans?" She covered detailed aspects such as multiple concussions, the force of a blast, multiple disabilities as well as complications of alcohol and prescription drug addiction.

Laura Gomez and Alfonzo Molina of the Palo Alto Veterans Affairs Poli-trauma Unit discussed how these services were provided, who they provide referrals in the community and ways of developing relationships for cross referral in the future. They provided a list of the case managers throughout the state.

Chris Lopez, a former Veterans Affairs employee who sustained a TBI while in Iraq, discussed the many ways of doing outreach to veterans. Some examples he used included:

Stand Downs: these are one-four day around-the-clock events for homeless veterans. Stand Downs have many volunteers from service organizations in the region offering services to allow veterans the opportunity to reintegrate into the community using the available resources. These services can include: having judges to reduce or dismiss sentences, upgrading discharge status from the service, grooming, housing, VA services and employment assistance. Chris also discussed what being a veteran with a TBI is like. He talked about the impact it had on his family and the support that helped him reintegrate into the community. Chris mentioned the difficulty he still experiences with not remembering things that he felt should come easy to him and how he used memory tools to be able to work with a TBI.

Department of Rehabilitation, Independent Living Centers & Traumatic Brain Injury Service Sites Collaboration Webinar

The audience for this webinar included Department of Rehabilitation (DOR) staff, Independent Living Center (ILC) and TBI service site staff and members of the Statewide TBI coalition. We focused on this selective audience because of the specific nature of the content and tools being provided.

Presenters included Ana Acton, Chief of the Independent Living and Assistive Technology Section (ILATS, DOR) and Dan Clark from the Community Resources Development Specialist (CRDS), ILATS DOR. Both addressed DOR's vision around TBI. The presenters focused on how they wanted TBI service sites and ILCs to work together with the 'no wrong door' approach. They provided examples of cross-referral and the concept of developing a Memorandum of Understanding to delineate each party's role in the process. They also gave information about the differences between IL philosophy and the medical model as well as the role of the support network for the TBI consumer.

Presenters Doug Chandler, CCCIL's TBI Awareness Project Manager and Crystal Cardenas Loutzenhiser, CCCIL's TBI Awareness Project Assistant, discussed why TBI is important to the audience including the perspective of an individual consumer with a brain injury and the more global perspective of the large number of people that have a TBI. This included discussion of the tools that have been and are being developed through this project to allow service providers to better serve consumers with a TBI. These tools include the various components that are being developed in the resources tab under tool box on this catbi.org website.

Webinar Planning Guide

A webinar planning guide was created to provide a step by step sequence on how to put on a successful and accessible webinar. This includes coming up with the concept, arranging speakers, notifying the audience,

creating the content and PowerPoint, tracking the number of participants and asking participants to complete both pre- and post surveys.

YO! Disabled and Proud (Youth Organizing) Webinar

A webinar was developed for youth and was designed to provide information about TBI in a youth friendly format. This included interactive questions and answers, using the polling feature and video clips of youth. Both youth members of YO and service providers to youth participated in the webinar. We discussed the prevalence of TBI amongst youth including veterans and strategies for living with a brain injury.

Assistive Technology (AT) Webinar

An Assistive Technology (AT) Brown Bag Webinar presentation took place for members of the AT network. Participants from the TBI Service Sites were invited to participate. This webinar allowed participants to learn and share their expertise on accommodating the different functional areas that need to be considered when serving a consumer with TBI.

The functional areas included: Memory, Physical effects and Cognitive Sensory Emotional/Behavioral. There were portions of the Webinar presentation that allowed feedback from participants to be written for the audience to see.

Webinar Summary

In the earlier stages of this program a great deal of time was spent collecting data. This was the emphasis of the first phase of this project. The purpose is to have well documented baseline information from key stakeholders. The baseline information will serve to make informed decisions for suggestions about advocacy, increasing awareness and public policy. This input will be helpful when generating media attention from consumers and a variety of service providers.

The webinars provided a strong foundation to advocate for needed changes in the delivery of services to consumers with TBI. This was followed by forming and convening the TBI Advisory Committees. These committees have provided a consumer perspective which was reflected in the first nine webinars. A strong foundation was developed for educating the community and working to improve the lives of consumer with TBI.

The Youth webinar and Assistive Technology webinars were arranged through CFILC to expand the training on TBI to other populations.

For more information on our **webinars**, these documents are available and located on the thumb drive provided with this report:

➤ **Webinar**

- ⇒ [Webinar Planning Guide](#)
- ⇒ [Webinar – RFP for Real Time Captioning](#)
- ⇒ [Webinar – Webinar Instructions Template](#)
- ⇒ [Webinar – Sample Webinar Orientation](#)
- ⇒ [Webinar – Pre-Webinar Survey](#)
- ⇒ [Webinar – Post-Webinar Survey](#)

➤ **Statewide TBI Webinar Power Points**

- ⇒ **1 – [Improving Service Coordination for People with a TBI](#)**
- ⇒ **2 – [Veteran Culture and Service Coordination](#)**
- ⇒ **3 – [Building Collaboration between DOR, ILCs and TBI Service Sites](#)**
- ⇒ **4 – [Issues Impacting Youth with TBI](#)**

Outreach – Building Community and Regional Partnerships

Veteran Outreach and Collaboration

Joining the Monterey County Veterans Mental Health Task Group provided valuable contacts with people who work for agencies that provide direct services to veterans. This task force was requested by the Director of the Commission on Behavioral Health. Thus far we have drafted a proposal with a budget to approach funding sources. The proposal emphasizes expansion of services under Veterans Affairs contract to include Veterans' with TBI and Post Traumatic Stress Disorder (PTSD). We also met with Roger Brautigan, former Secretary to the California Department of Veterans Affairs, who showed interest in collaboration with community partners and the services available through ILCs.

This task force is now called the Monterey County Veterans Collaborative. It has grown from ten members to approximately 100 members and encourages consumers to participate in the discussions and to serve on the committees. Subcommittees were established to address communications, transportation and to create a Veteran's Drop-In Center. Other issue areas that were addressed include housing (the HUD-VASS program), forming a Veteran's Court and having a stand down in Monterey County.

The California Statewide Collaborative on Veterans' Services meets at Moffett Field in the Bay Area. It is comprised of an exciting group of people who provide services to veterans. There are approximately forty participants including the coordinator, Mary Ellen Salzano, that meet every six weeks to discuss a variety of topics related to serving veterans with TBI. The Collaborative has developed an expansion model has been developed for regions throughout California.

The Collaborative included a veteran's representative and disabled student services counselor at the local community college that provide an excellent resource for information on services provided through ILCs and TBI service sites. When approaching our local community college, they were particularly interested in support groups for people with TBI. They indicated that they have had a large increase in the number of people with TBI registering for classes. We have found that veterans with TBI are coming to colleges in increasingly larger numbers and seeking a variety of services. Serving this population has presented some challenges because of the wide range of services needed for people with TBI and the decrease in available funding.

Civilian Outreach

Civilian or non-veteran outreach has allowed us to collaborate with a variety of organizations that serve people with TBI. The California TBI Coalition hosts conference calls scheduled by Lynda Eaton of Mercy's Home and Community Program and facilitated by Todd Higgins of Disability Rights California. This is an opportunity for organizations in California that work with consumers as well as consumers with TBI to share information about topics such as new legislation, outreach and upcoming event information. The seven California TBI Service Sites are also a valuable resource throughout the state and many of them participate in this collaborative.

The Community College Disabled Student Services Programs also offer programs that help people with TBI. This can include classes on Learning Skills such as: memory enhancement, using assistive technology, organizational skills, thinking and reasoning, auditory processing and college success. Because of these types of programs, community colleges are often good resources. Their school counselors can let students know about the programs offered by ILCs and other community organizations.

Coordinating with support groups for consumers with TBI and their caregivers were helpful in identifying resources for consumers with TBI. Outreach to these groups provides an opportunity for TBI networking.

The Traumatic Brain Injury Resource Directory (TBIRD) is a resource that lists numerous programs and services offered for people with TBI and their caregivers. This resource guide began in the Santa Clara (Silicon) Valley and provides in-depth information on available resources that extend beyond brain injury. The most comprehensive information is available for the San Francisco Bay Area; however, information on a number of statewide resources is also available. Unfortunately this is not available online currently but is available in CD format.

For more information on **TBI Outreach**, these documents are available to download (located on the thumb drive provided with this report):

- [Sample TBI Outreach Presentations](#)
- [Stop Flyer](#)
- **TBI Brochures**
 - ⇒ [Have you sustained a TBI?](#)
 - ⇒ [Did you know?](#)
 - ⇒ [Veterans: Have you heard?](#)
 - ⇒ [Veterans: We are in this together](#)

Working to Integrate Civilian and Veteran services is critical for being able to provide quality services and making resources of ILCs, TBI Service Sites and other community organizations available.

California Traumatic Brain Injury (CATBI) Website

The mission of the www.CATBI.org website is to increase TBI awareness and promote appropriate, accessible services throughout California for people living with a TBI. Individuals with TBI serve a crucial role in determining the information that is posted on this website. An electronic copy of this manual and links to the webinars are available on this website.

This website was created as a bilingual English/Spanish

website as a resource for all consumers, caregivers and service providers to become more informed about TBI.

Public Policy Handbook

Charlotte Newhart, the public policy consultant for this project, has worked to increase TBI awareness amongst family physicians. Family physicians are considered the gatekeepers of medical care to people with TBI. Charlotte arranged a meeting with the advisory committee, CCCIL staff and the people creating curriculum for a continuing education program that is being generated by the California Academy of Family Physicians. This allowed consumers to have input on the types of issues that can be addressed by family physicians.

Charlotte also provided regular updates on legislation effecting people with TBI and ideas for addressing these issues.

Plan to Track and Act upon Legislation: Democracy works best when all citizens participate in the process

There are many ways an individual or group can affect California policy regarding Traumatic Brain Injury (TBI). You can vote for responsible individuals in your community, inform them and their staff about TBI invite them for visits to local ILCs, send letters to District offices, submit letters to local newspapers and invite legislators and/or staff to meet with TBI survivors. If you tell your story and share specifically what you need, you can make a difference.

The California Legislature considers issues impacting individuals with TBIs on a regular basis.

Individuals and groups do impact the development and results of bills introduced in the state legislature. The process only works effectively when

individuals tell their stories through letters, phone calls, e-mails, and testifying in person at Committee hearings on bills that matter to them.

How a bill becomes a law in California

At the beginning of each year, legislators in the first two months introduce “bills” which are designed to create changes to existing CA laws. Some bills remove old or outdated laws; others create new programs and/or penalties. For example, a recent bill was proposed that would change existing state laws and require snow sport helmet use for all persons under 18 years of age.

A bill then follows very specific steps before it can become a law in CA and all steps of the process allow and encourage citizen participation in the process.

Step One- Assignment to Committee & Public Input

Once a bill is in print it is assigned to a policy committee (health bill to Health Committee, etc). Committees are composed of legislators in both parties however the party with the most members in the Assembly or Senate gets the most seats in the committees. The Chairs of the Committees also tend to be from the majority party, while the Vice Chairs often will be from the minority party.

A hearing, which is open to the public, will then be held on all bills. Committee staff will have prepared an analysis on each bill to be heard including cost estimates, history of the issue in California, and a list of all letters, phone calls, and e-mails received for and against the bill. A letter from a TBI Center or individuals with TBI would have significant impact on a TBI related proposal. At this time, anyone from the public can send a letter and/or testify at the hearing requesting a “Yes” or “No” vote on the proposal and their reasons for their position on the bill.

This process is only considered “lobbying” if one is a registered lobbyist and being paid for their professional services. For the general public this is considered participation in the democratic process.

Step Two- Appropriations Committee Fiscal Impact

If the bill passes the policy committee it then goes to the Appropriations Committee which considers only the fiscal (cost) impact of the proposal. Generally, if a bill is estimated to be at or above a set financial threshold (\$50,000 example) the bill will be placed in the SUSPENSE file, a temporary file for bills so that all can be reviewed at one time and priorities made for those costing California money.

All money bills will be reviewed by the Appropriations Committee members and either held in Committee Suspense file or passed by a vote of the Committee to continue their journey to Step Three.

Step Three - Assembly or Senate Vote

The bill that has survived the steps above will now head to the Assembly or Senate floors where majority vote on most bills is required. The bill must pass in the house of origin (Assembly/Senate) by a majority vote in most cases before it can continue the journey to the next house where the above process is repeated.

Final Step - Governor Signs or Vetoes the Bill

Once a bill has passed both houses of the legislature it now goes to the Governor. At this point the Governor can sign the bill into law, or he can veto the bill, thus killing the proposed legislature.

Road Map - Following the Bill

- Bill Introduced by a Legislator
Repeat Process in second House (either Assembly or Senate)

- Appropriations Committee, Floor of the House (Assembly/Senate)
- Returns to House of Origin for body to consent to changes made in second house
- To Governor for Signature or Veto

There are three major sources for obtaining information on bills and the progress of the bill:

- www.leginfo.ca.gov: This website gives calendar information of all bill hearings, has an events search mechanism for specific bills, a California law section, subscription services with the option for e-mail notifications when there is action on specific bills, links to the Assembly Daily Journal, the Senate Daily Journal and the State Net National service- a service that covers state and federal activities (this is a subscription service that, while costly, has thorough information and is timely).
- Call Legislative offices or visit individual web sites with information on their bills Pocket Directory of CA Detailed information on individual legislators, committee membership, etc

Legislative Visits

There are two types of legislative visits. The first is called a “meet and greet” and the purpose is to introduce yourself and your cause to the legislator and their staff. This is an opportunity for briefing a legislator on your issues and letting him/her know who you are and that you are a resource for information regarding TBI. Always leave printed information and contact information with the legislator and the staff so they contact you easily if questions arise after the visit.

The second type of legislative visit is where one is requesting the elected official to support or oppose a specific proposal being considered by the legislature. This could be in a committee hearing on a bill about TBI or when funding for TBI comes before the budget committees or a bill is being considered on the floors of the Assembly or Senate. It is crucial to have a letter and/or documents outlining the reasons for your support or opposition to the bill, which can be left with staff and/or the legislator.

Regardless of the purpose of the meeting, the process is always the same. You can contact the office either in the legislative district or in their Sacramento office for an appointment (federal representative meetings will most likely occur in the district). No more than three or four individuals should attend a meeting as one will have limited time and it is important to use it wisely.

One should meet with the group going to the meeting prior to the visit to identify a lead person and who will cover each issue. Allow time for the legislator/staff to ask questions and become educated (again, be sure to bring written information to leave with office in case you are unable to get through everything during the meeting).

Thank the legislator for his or her time and be sure to leave your contact information with staff that was in the meeting. A follow-up note to the office thanking them for the meeting is both thoughtful and a reminder of the issues you are advocating.

Contacting State Senators and Assembly Members:

- Local Telephone Book, Under Government Pages
- State Government Offices
- CA Secretary of State Office (web: www.sos.ca.gov)
- CA State Government Information (State Capitol: 800-807-6755)
- Other useful resources:
 - Capitol Enquiry, Pocket Directory of the CA Legislature: e-mail: info@capenq.com, website: www.govbuddy.com

Sample Letter to an Assembly Member who is the author of a bill:

The Honorable Tim Jones
California State Assembly
State Capitol
Sacramento, CA 94814

RE: AB 1800 (Smith) Increased Medical Benefits

For Persons with TBIs
Position: SUPPORT

Dear Assembly Member Jones,

I strongly support AB 1800 (Smith) which would increase medical benefits for persons with Traumatic Brain Injuries. I am a person with a TBI and have had difficulty obtaining medical insurance and care. This bill would help me do both.

Thank you for your leadership on this important issue. (or if to members on a committee hearing the bill: substitute: 'pleased vote for this important bill')

Sincerely,

Full name

Address (street & city)

Grassroots Activities and Advocacy

Self Advocacy

An important part of this project was helping people with TBI learn to advocate on their own behalf. At a number of meetings, participants voiced significant frustration with the medical community and their lack of understanding of the problems people with TBI face on many levels.

Step one in dealing with this frustration was to identify an issue and try to get a clear definition of the problem. In this case, the problem was narrowed down to general and family physicians who are the primary care provider for people with TBI and are not trained to deal with the long term effects of TBI or their impact on individuals everyday lives.

The next step was to have the focus group identify the problems they experienced. A list was developed and specific priorities were outlined. It was determined that staffs in physicians' offices lack the experience about the impact of TBI on patients; for example: the longer time needed to fill out forms, etc.

Other specific problems discussed were patients having difficulty understanding instructions especially when given verbally in a short time frame and problems consistently following instructions.

Income limitations or problems dealing with forms (such as MediCal) often occur because people did not know where to go for financial aid or other assistance. Also, undependable transportation would sometimes cause them to be late or miss appointments and disrupt schedules.

How does one create change?

- Clearly define the issue
- Identify who can make change or influence behavior for change
- Meet with those individuals, groups, representatives who can assist or create needed changes

A Model for a Plan of Action

- A consultant met with staff from the California Academy of Family Physicians and invited them to meet with TBI survivors
- They immediately accepted, as their membership had expressed frustration with not having the proper tools or training on how to provide quality care to TBI survivors in the present system of medical delivery
- A meeting was arranged for senior staff of the Family Physicians responsible for continuing medical education to meet with the TBI community to discuss the issues.
- The TBI community engaged in discussions to develop priorities of their concerns and issues in preparation for the meeting.
- The meeting was held in Salinas and each TBI survivor present shared their experience both personally and with the medical system.

While change can sometimes be slow, it was an empowering experience for the TBI community and for the family physicians representatives who have begun work on a comprehensive continuing medical education program for physicians.

One of the significant lessons learned is the importance of outreach beyond our community to educate and to build partnerships which can lead to change that is valuable for everyone.

The limited timeframe of the grant and the narrow definition of advocacy reduced our ability to pursue a true grass roots campaign. But there are many roads to achieving desired change. The materials, resources, and experiences provided in this initial grant will provide tools and hopefully the desire to do more aggressive organizing and sharing of personal

experiences with individuals that can assist them in making positive changes for the TBI community. If people at decision making levels do not know a community in need exists and what those needs are they cannot help.

Media Outreach Handbook

Paschal Roth, our media outreach consultants, created a comprehensive Media Outreach Handbook called “Expanding TBI Services Manual”. This provides information about how to get media to come to and properly cover events, the elements of a good news story, and sample articles and letters to the editor.

Media Outreach Handbook Overview

In November 2009, Central Coast Center for Independent Living (CCCIL) received a one-time grant from the California Department of Rehabilitation – made possible through President Obama's American Recovery and Reinvestment Act of 2009 – that enables the nonprofit group to develop a model for California and build capacity to serve civilians and veterans with traumatic brain injuries (TBI). The Salinas-based organization serves residents of Monterey, San Benito and Santa Cruz counties.

Part of that grant entailed putting together an “Expanding TBI Services Manual” to be used at independent living centers, TBI sites and organizations across the state. The manual covers many aspects of TBI outreach, including media outreach to raise awareness of TBI and TBI resources. In order to fulfill this goal, CCCIL partnered with the media-consulting firm, Paschal Roth Public Affairs, to develop a comprehensive handbook for TBI organizations in conducting media outreach.

All the information compiled is based on Paschal Roth's experience as media consultants and former journalists, a survey of news stories centering on TBI organizations and programs published within the last year, and interviews and survey responses from TBI organizations across the state about their media outreach efforts.

For the purposes of this report, we interviewed and collected data from the following TBISCA organization throughout the state: the Central Coast Center for Independent Living in Salinas; St. Jude's Brain Injury Network in Brea; the California Brain Injury Association in Bakersfield; the Making Headway Center in Eureka; the Betty Clooney Foundation in Long Beach; and Services for Brain Injury in San Jose.

Earned Media

What is earned media?

Earned media refers to publicity outside the realm of paid advertising. Earned media typically involves outreach to editorial boards, newsroom staff, assignment editors and journalists to submit or pitch news stories and story ideas. It includes mass media outlets such as radio, television, newspapers, the internet, blogs and social media and may include a variety of formats, such as news articles, TV news segments, letters to the editor, and editorials.

Why do earned media?

For organizations that do not have the benefit of a large budget to purchase online, television or radio advertisements, earned media can be a cost effective alternative. It allows organizations to limit their expenses and still reach a wide audience.

It also has other advantages over paid advertising. Whereas paid advertisement typically are confined to 30-second to one-minute durations on television or space limitations in print publications and online ads,

earned media pieces are lengthier and more in-depth than your typical paid advertisement, and allow you to tell more about your organization or issue.

Earned media can also offer continued payoffs long after the initial story. As you develop relationships with journalists, you also develop the opportunity to become their go-to “expert” on issues. Many TBI organizations that have worked with journalists in the past find themselves being asked to comment on stories related to TBI. This repeat coverage can lead to increased visibility, both online and in the community.

For grassroots TBI organizations aiming to expand their services, news stories can get the word out about your services and lead to additional clients and consumers. Claudia Ellano-Ota of St. Jude’s Hospital said of earned media, “Our experience with media has been that that’s where we get most of our referrals from.”

How do I reach out to media?

There are generally three steps in media outreach. The first involves putting together a newsworthy event and inviting media to cover it. This typically includes drafting a news advisory and press release⁶. News advisories include the date of your event, a contact person and phone number, a newsworthy headline, and two paragraphs giving the essential details about your story. It is often useful to include a list of who, what, when, and where at the bottom of your advisory. Advisories usually are written for events happening at a specific day and time, such as a news conference or a rally.

The second step in media outreach is directly contacting newsrooms and journalists to pitch story ideas. One of the best ways to do this is through a targeted search of a newspaper’s archives to find the journalist who covers the topic closest to your issue. You can also speak directly to the news editor to pitch a story idea.

⁶ See appendix for sample news advisories and press releases

Once contact has been made with the newsroom, the last step is to submit a press release. Press releases are similar to news advisories. They are generally expanded news advisories that include additional information and quotes from officials. They are generally sent to newsrooms and reporters shortly after or a day after the event happens.

The key to generating media interest is having a compelling story and pitch. Every news story has its essential components. You want to incorporate as many of these components as you can into your pitch to make your story idea persuasive to reporters and editors. The following section will help you gain a better understanding of what makes a compelling news story and what goes into making a successful news pitch.

Key Elements of a Good News Story

A good news story will have four key elements:

When approaching a reporter about a program or issue, making sure to have these lined up ahead of time will help you get your message out.

- **"Hook"** -- what is timely or urgent about this issue. Why is it important for the reporter to write the story NOW?
- **Expert** -- Have a person lined up who can give data about the issue (how many people are affected? Who are they? Where are they?)
- **Human Element** -- Have a person lined up who can share their personal experience around an issue, to show the program is more important than just numbers.
- **Designated spokesperson** - It's always helpful to have someone that is familiar with your messaging and goals for the interview. Make sure this person is prepared with talking points ahead of time.

Some added pointers for drawing earned media attention to your issue include:

- **Promote local programs and events** – newspapers want to inform readers of what is going on in their community.
- **Respond to what’s going on in the news** – this will ensure your pitch to news outlets will be timely and relevant.
- **Establish relationships** – establishing relationships and connecting with journalists will help you get your message across and draw attention to your issue.

To develop an effective news hook, you need to incorporate some or all of these elements into your pitch to news outlets. The following section will expand on each of these points. There may be overlap between sections, but the idea of these points is to provide a frame of reference and best practices for conducting media outreach.

“Hook”

Every news story needs to have a “hook” – a compelling reason for people to read or watch the news piece. News hooks can be compelling human interest stories, important legislation that affects a large number of people, or new and interesting studies and statistics. The hook should answer the question, “Why should I care about this?” or “Why is this important?” Usually, the hook illustrates the scope of an issue, provides readers with context, and tells us who is or potentially could be most affected. To develop a successful news story pitch or draft an effective news advisory, it’s essential to have a compelling news hook.

One of the more common news hooks in stories about TBI recently has been veterans returning home with TBI. This news hook is particularly important for many reasons: It’s a national issue, for one, and is related to the wars in Iraq and Afghanistan, an issue that most Americans are concerned about. It’s also becoming a large-scale problem, with TBI now

being called one of the signature wounds of the wars in Iraq and Afghanistan. But most importantly, these stories have a strong human element by offering real life examples on the toll the wars have had on many of our servicemen and women.

The uniqueness or significance of an event or a TBI program can be a strong news hook. If a conference you are hosting is the first of its kind, playing that aspect up can be useful in your pitch or news advisory. In surveying many of the stories featuring TBI, organizations emphasized a special program that is the first or only of its kind.

“News you can use” – stories that provide information readers might find relevant and useful – is another popular hook in news stories. These stories are also useful for expanding services to TBI because they can help people realize if they or a loved one might have TBI. Claudia Ellano-Ota of St. Jude’s Brain Injury Network said, “One of the things that have been most helpful has been a ‘What is TBI?’ story we got placed in the paper. We got about 200 calls from that newspaper article, and some of the callers were people who really did have brain injuries.”

A great way to develop a sense of what a strong news hook is to read news articles and ask yourself what the main point of the story was and why the journalist thought it was of interest to readers. As you familiarize yourself more with journalists’ and reporters’ style and writing, you will develop a firmer grasp of what journalists find interesting and what makes a strong news pitch.

Expert

Every news story contains at least one quote from an individual. Reporters always expect to talk to a source for quotes, and for stories involving technical subject matter; they will often look to experts to use as sources in their news stories. Journalists look to these experts to provide context,

perspective and knowledge on an issue. Experts provide background information and make an issue more understandable to readers and viewers. Having a go-to person to field these questions can be useful for pitching news stories. Ideally this person will be the most well versed person on TBI and issues surrounding TBI, or the person most familiar with your messaging.

Journalists often look to experts to provide “hard data” such as statistics, numbers and overall trends. Here are some examples of information provided by TBI experts in recent stories:

- Deemed the “silent epidemic” because it often goes undiagnosed, traumatic brain injury affects 1.7 million people and kill 50,000 people a year, according to the Center for Disease Control. It’s been estimated that there are approximately 225,000 survivors of traumatic brain injury (TBI) in the State of California.
- TBI can affect anybody. Injuries can be sustained in falls, sports injuries, car accidents or collisions.
- TBI has been referred to as the signature wound of the wars in Iraq and Afghanistan, with government reports finding that 65 percent of veterans from Iraq and Afghanistan treated at Walter Reed Hospital were diagnosed with TBI.
- The Center for Disease Control estimates that 300,000 student athletes suffer concussions each year.
- TBI is the leading cause of severe disability in young Americans age 15-25 and some 2 million suffer a year.

Not all statistics, though, have to be negative. If a TBI organization can provide statistics and background on positive outcomes for TBI consumers that can be a strong selling point for a news story as well. In addition, one of the benefits of having an expert in your organization is that journalists will often come back for comments on related stories. For example, if they have a story about legislation relating to TBI, they may contact a TBI expert from a previous story for comment. This can then translate into added visibility for your organization or issue.

Designated spokesperson

The designated spokesperson can be an expert, a consumer with TBI, a staff member or others familiar with the issue. These designated speakers can benefit from media training and preparation before speaking to reporters. For those who are speaking to the media as experts on the subject of traumatic brain injury, talking points can be a useful tool for communicating their points effectively and staying focused on messaging. Taking time to craft the right message that resonates with readers and highlights the important aspects of your organization is an important aspect of earned media.

That's why it's beneficial to have a designated spokesperson delivering that message. Who the appropriate spokesperson is dependent upon what sort of story it is. For stories providing general information about TBI, the most knowledgeable person or the person most familiar with messaging might be appropriate. For consumer-focused stories, someone with TBI who is familiar with the services provided by your organization might be a better spokesperson.

Designated spokespeople can also be those with TBI who are willing to share their personal stories. For human interest stories, talking points and preparation may not be as necessary, since these stories play up the personal aspects of a story. Providing talking points and over-preparation may dilute the human-interest aspect of the story. However, if there is added information that may be more technical in nature, yet still relevant to the story, talking points can be a useful tool.

This leads into the next point of the report, the human-interest aspect of a story.

Human element

Stories that have a human element to them, also known as human-interest stories, are ones that tend to focus on a particular individual and discuss a personal experience. Human-interest stories are a great vehicle for TBI because TBI is an injury that is so often misunderstood. Putting a human face on TBI can humanize the story. They can also make what may be an abstract notion more relatable for readers.

However, personal stories involving TBI can be difficult for people to share. It's important to be sensitive to consumers' feelings when soliciting people to share their stories. Some consumers may not want to be labeled as having TBI. Make sure to obtain their permission as well as their families' permission before pursuing a profile story.

These stories are often much more in-depth than your typical news story. They also create the most memorable impression among readers and can make a strong complement to hard statistics and numbers. While having statistics and numbers to illustrate a point (e.g. the increase in the number of veterans with TBI), human-interest stories tend to leave a strong impression on readers than statistics.

Carol Welsh, a volunteer and the current public relations staff member for Service Brain Injury of San Jose, has one example of such a story. Welsh's husband had a TBI following a motorcycle accident. Welsh and her husband regularly speak to the public to raise awareness of TBI. They shared their story with the Mercury News for a story and video titled "Relearning how to live" that told of their experience dealing with the aftermath of a TBI and how Services for Brain Injury were able to help Welsh's husband relearn basic tasks following the accident. The article also mentioned that Services for Brain Injury was taking donations to help construct a fully-equipped Life Skills Lab for TBI survivors. Welsh says the

story and the video in the Mercury News helped raise close to \$10,000 in donations.

New York Times journalist Nicolas Kristof wrote, “As we all vaguely know, one death is a tragedy, a million deaths is a statistic. As Mother Teresa said, ‘If I look at the mass, I will never act. If I look at the one, I will’... psychological research shows that we are moved not by statistics but by fresh, wet tears, with a bit of hope glistening below.” Sharing personal stories of TBI taps into readers’ empathy and creates a much more powerful message than a typical hard news story.

Promote local programs and events

One of the more recent trends in journalism has been a shift in emphasis towards local, or community, journalism. This type of journalism aims to cover stories that are of interest to residents and better inform readers of news that is happening in their community. This trend works in favor of local grassroots organizations.

Generally speaking, readers and journalists are more receptive to positive local news stories, especially ones about events or programs that benefit local residents in some way. For example, the Making Headway Center in Eureka set up a TBI safety education campaign aimed at local high school students in the community. Sylvia Soper, Administrative Coordinator of the Making Headway Center in Eureka, said, “In our experience, positive stories, such as ones about prevention efforts and helmet giveaways, attract much more attention than dire ‘this could happen to you’ stories.”

Aside from news stories, you can also reach out to local newspapers for announcements, news briefs or calendar listings. The main selling point is that the stories are local and relevant to the community.

Conversely, however, if your event is big enough, the significance of the event could be a selling point as well. The California Brain Injury Association in Bakersfield held the first ever Senate Information Hearings on Brain Injury last year. It was a historic hearing where for the first time advocates briefed lawmakers on current gaps in coverage and treatment

for TBI victims. Paula Daoutis of the Brain Injury Association of California said they were able to bring a TV news anchor from KGET in Bakersfield with them to Sacramento to cover the hearings. That story then evolved into a four-part segment called “The Silent Epidemic” that took a comprehensive look at TBI from a variety of perspectives. It included interviews with TBI organizations, doctors, profiles, and general information about TBI.

Respond to what’s going on in the news

Another quick and easy way to get placed in the media is by commenting on or responding to news stories. This requires keeping up with TBI-themed stories. Carol Welsh of St. Jude’s Brain Injury Network says, “Following the media is a big part of it [media outreach]... Generally you have to think about how you can get ahead [of the news]... part of it is luck, but a big part of it is also knowing what is going on out there in the community.”

There are many ways to go about commenting on a story. One way is to directly call reporters about a TBI-related story and offer to get them in touch with an expert or consumer who can speak more on the subject. You can also submit statements by one of your organization’s leaders providing comment on a relevant news story, such as TBI-related legislation being passed or a new study on TBI being published.⁷

Letters to the editor are another opportunity to chime on to TBI issues. They allow TBI organization to educate readers. In doing so, they can allow writers to make plugs for your organization and your issue. Letters to the editor are generally short, usually no more than 200-250 words in length.⁸

To keep abreast of the latest news, we recommend creating a Google News Alert for “traumatic brain injury” and “traumatic brain injuries” at www.google.com/newsalerts. You can also make your alerts California-specific by adding “location: ca” to your alert phrase (e.g. traumatic brain

⁷ See appendix for sample statement

⁸ See appendix for sample letters to the editor

injury, location: ca). We also recommend regularly scanning your local newspaper for any stories that might be of interest.

Establish relationships

Paula Daoutis of the California Brain Injury Association lists making good connections with the media as one the best ways to generate media interest in TBI, and rightly so. All the TBI organizations we interviewed listed this as an important component of media outreach.

Credibility means a lot when working with the media. Reporters often have a “stable” of go-to sources that they use for different issues. Building a strong rapport with a reporter, editor or TV news assignment planner can help immensely when you’re holding an event or pitching a news story. Keep in mind when approaching journalists that you are helping make their job easier.

The importance of relationship goes beyond the media and extends to forming relationships with other TBI organizations within the region as well. In the case of the federally funded Betty Clooney Foundation, they receive more media requests than they have capacity for. As a result, they will occasionally refer media inquiries to other local agencies and TBI organizations. Partnering with larger TBI organizations, such as federally funded organizations that are more visible can be beneficial. Forming a relationship with such organizations can become an opportunity to connect with journalists looking for an expert perspective on TBI and a chance to increase your organization’s profile.

Sample Media Material and News Clips

Sample News Advisory:

FOR IMMEDIATE RELEASE

June 29, 2010

Contact: Mike Roth, (916) 444-7170

With Growing Need for Services for Returning Vets, Central Coast Hosts Traumatic Brain Injury Conference in Salinas

Joined by CA Deputy Secretary of Veterans Affairs, Group Unveils Mobile Veterans Outreach Clinic to service the Region

Salinas, CA – As part of a new effort to assist those living with Traumatic Brain Injury (TBI), TBI survivors, families, experts and care providers will gather Tuesday for the Central Coast Center for Independent Living's conference, "Traumatic Brain Injury Awareness: Connecting Needs and Services." The day-long event is part of a new effort to reach out to veterans with TBI, and aims to raise awareness of TBI, educate residents on what services are available locally to those with TBI, and introduce the Mobile Veterans Outreach Clinic to attendees.

The event, which will take place at the Northminster Presbyterian Church Conference Center, will introduce participants to the new Mobile Veterans Outreach Clinic which will service region.

As one of 50 mobile vet centers across the country, it will provide readjustment counseling and information resources to veterans with TBI, and help them make the difficult transition between military and civilian life,

or for active duty personnel, the transition from a combat zone to a peace time garrison environment.

What: Day-long TBI awareness conference and Mobile Veterans Outreach Clinic showing

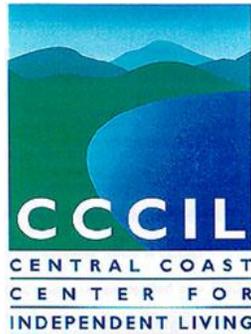
Who: TBI care providers and consumers, speakers include Puntillo, Deputy Secretary of Veterans Services of the California Department of Veterans Affairs and Dr. Harriet Zeiner, lead clinical neuropsychologist for the polytrauma center at the Palo Alto Veteran Affairs hospital.

When: Tuesday, June 29, 8:30 a.m. to 4 p.m. Press conference and Mobile Veterans Outreach Clinic viewing from 10:30-11:15 a.m.

Where: Northminster Presbyterian Church Conference Center, 315 East Alvin Drive, Salinas

Visual: Mobile Veterans Outreach Clinic unveiling. Open to viewing by the media from 10:30-11:15 a.m.

Sample Press Release:



For Immediate Release
Kalhoefer

June 29, 2010

Contact: Kevin

916-444-7280

With Growing Need for Services for Returning Vets, Central Coast Hosts Traumatic Brain Injury Conference in Salinas

Joined by CA Deputy Secretary of Veterans Affairs, Group Unveils New Mobile Veterans Outreach Van to service the Region

Salinas, CA – As part of a new effort to assist those living with Traumatic Brain Injury (TBI), TBI survivors, families, experts and care providers gathered today for the Central Coast Center for Independent Living’s conference, *“Traumatic Brain Injury Awareness: Connecting Needs and Services.”* The day-long event raised awareness of TBI, educated residents on what services are available locally to those with TBI, and introduced the new Mobile Veterans Outreach Clinic to attendees.

“This unique event was meant to be a comprehensive source of information for those with TBI and their loved ones,” said Elsa Quezada, Executive Director of the Central Coast Center for Independent Living. “But it was also a great opportunity for folks with TBI and their loved ones to have meaningful dialogue with TBI care providers on the state and local levels and express their needs.”

The event, which took place at the Northminster Presbyterian Church Conference Center, introduced participants to the new Mobile Veterans Outreach Clinic which will service region.

As one of 50 mobile vet centers across the country, it will provide readjustment counseling and information resources to veterans with TBI, and help them make the difficult transition between military and civilian life, or for active duty personnel, the transition from a combat zone to a peace time garrison environment.

Keynote speaker and Deputy Secretary of Veterans Affairs for the California Department of Veterans Affairs Ted Puntillo emphasized the importance of treating veterans with TBI. TBI is becoming the signature wound of the wars in Iraq and Afghanistan, with government reports finding that 65 percent of veterans who served in Iraq and Afghanistan treated at Walter Reed Hospital were diagnosed with TBI.

“TBI is an extremely serious health issue with staggering amounts of service men and women with TBI,” said Puntillo. “When our veterans get home, we need to make sure that we are able to get them connected to the services and care they need, and the expansion of the Mobile Veterans Outreach Clinic is a big step in that direction.”

Deemed the “silent epidemic” because it often goes undiagnosed, traumatic brain injury affects 1.7 million people and kills 50,000 people a year, according to the Center for Disease Control.

“The important thing to know about TBI is that it can manifest itself in many ways and can often go undiagnosed or be misunderstood,” said Elsa Quezada. “That’s why opportunities like this to educate and connect people to TBI services are so important.”

Sample Statement:

FOR IMMEDIATE RELEASE

November 2, 2010

Federal Government Approves Sweeping Changes to Improve California's Health Care Safety Net

SACRAMENTO, CA – The Service Employees International Union (SEIU) California released the following statement from President Bill A. Lloyd today on news that the federal Department of Health and Human Services has approved sweeping changes that will strengthen California's health care safety net:

“Today's decision is great news for all Californians who count on public hospitals and emergency rooms to be open when they need care. The federal government's approval of our state's wavier application means additional dollars for public hospitals that have struggled to provide health services to all Californians who need care, and builds the funding bridge California needed to implement of federal health care reform.

“The bi-partisan coalition that came together to support these changes can be proud that we have strengthened our health care safety net by expanding Medi-Cal, bringing additional dollars to California, and creating a more effective, coordinated system of care for seniors and people with disabilities while reducing costs.

“This victory was only possible because a broad coalition of public and private hospitals, health care advocates, our Congressional delegation, Governor Schwarzenegger, SEIU, and the Obama Administration came together with the goal of improving health care for Californians. Working together, we put California at the forefront of implementing the national health care reform, and that means better health care for all Californians.”

Recent news articles featuring TBI organizations:

The Salinas **Californian**

Returning Monterey County veterans learn to live with traumatic brain injuries

November 11, 2010

For two years after her return to Monterey County, retired U.S. Army veteran Jeanne O'Brien wondered about her sanity.

Injured while stationed in Afghanistan during Operation Enduring Freedom, the Marina resident recalled Tuesday that it wasn't until she went to the Veterans Affairs Palo Alto Health Care System in May 2009 that she learned the reason for her memory loss, problems with thought and speech processes and motor deficiencies that is keeping her in a wheelchair as a precaution.

Traumatic brain injury, O'Brien explains, a condition she received in 2007 while guarding ammunition that was awaiting pickup from another company. O'Brien, 40, a driver for the U.S. Army 82nd Airborne division, said a gale force wind had knocked over a piece of plywood which then struck the back of her head. She said her head bounced between the plywood and a metal can used to store the ammunition.

"I can laugh about it now, but it really isn't funny," O'Brien said. "The army didn't say I had it [at first]. I didn't find out until I was dealing with [the VA in] Palo Alto. That was two years ago ... two years of wondering if I was going crazy."

As the nation celebrates Veterans Day, a nonprofit organization — the Central Coast Center for Independent Living — hopes to raise awareness of traumatic brain injury among returning veterans from Iraq and

Afghanistan and the services available for these men and women as well as their families.

In November 2009, CCCIL received a one-time grant from the California Department of Rehabilitation — made possible through President Obama's American Recovery and Reinvestment Act of 2009, according to its website. The grant enables the nonprofit group to better serve veterans and other survivors of traumatic brain injuries. The Salinas-based organization serves residents of Monterey, San Benito and Santa Cruz counties.

The core services the organization provides in the program are support groups, information and referrals on housing and legal issues, technological assistance and self advocacy, said Doug Chandler, the traumatic brain injury expansion project manager, on Tuesday.

"[Traumatic brain injury] is deemed the silent epidemic because it often goes undiagnosed," Chandler said.

The condition is often undiagnosed, he said, because of the similarities in symptoms as post-traumatic stress disorder. Chandler said symptoms of the condition include memory loss, impaired thought processes, and vision and hearing problems.

There are nearly a quarter of a million survivors of the condition within the state, he said. According to the Center for Disease Control and Prevention, the condition affects 1.7 million people and kills 52,000 people a year. Traumatic brain injury is defined as an injury from an external blow to the head — from a bike or car accident to violence or a fall. Effects from the injury include anger issues, depression and memory loss.

Chandler said the group serves nine veterans right now through the program, which is one of seven throughout the state. The organization is trying to expand its services to veterans, he said. As part of its expansion efforts, Chandler said, an advisory committee of eight veterans with TBI was created to raise awareness and further education efforts. He said the program is also working on providing employment services for those with TBI as part of a pilot project.

There is a sense of immediacy, Chandler said, as the VA deals with a large number of returning veterans.

Officials said traumatic brain injury is becoming the signature wound of the wars in Iraq and Afghanistan. Government reports find that 65 percent of these veterans treated at Walter Reed Army Medical Hospital in Washington D.C. were diagnosed with the injury.

Because of her injury, O'Brien said, she now stutters — more so when she's nervous. Now on medication, she needs alarms to remember to take them. O'Brien said she doesn't read as well as she used to and has major difficulties remembering names and directions.

Bound by a wheelchair for fear of falling and injuring her head further, she said she's learning to walk again with the help of a physical therapist.

O'Brien said programs like the one CCCIL offers are crucial for veterans or other people with her condition, especially when it concerns raising awareness among their families.

"It's fantastic, but there are a lot of people I've come across who have TBI who don't know where to go," she said, adding that more publicity for these programs is needed.

Retired U.S. Army staff Sgt. Victor Estrada, 25, of Salinas, is also a survivor.

On Sept. 25, 2005, Estrada said, he was wounded by an improvised explosive device in Iraq. The roadside bomb took out half of his skull, he said, leading to a craniotomy. Estrada said the injury put him in a coma for a month, during which he had a stroke. When he woke up, he said, he found out he was paralyzed on his left side.

Estrada said he was in the U.S. Army's 1st Infantry Division — the "Big Red One" — and came out of the 75th Ranger Regiment. Before Iraq, he said, he served a tour in Afghanistan. For his efforts, Estrada said, he was awarded two Purple Hearts and a Bronze Star Medal of Valor.

For the past two years, he said, he has been going to the VA in Palo Alto regularly for therapy. Estrada said his left leg is about 90 percent healed and he can walk again. As a patient within the program, he said, his daily routine includes going through recreational and physical therapy, and attending support and cognitive training groups.

While it took him a while to seek help, Estrada encourages returning veterans to get assistance as soon as possible whether it is through support groups or therapy.

"They help you not just cope, but they teach you ways to deal with it to carry on with your life," he said

For more information about traumatic brain injury or to donate, visit the Central Coast Center for Independent Living's website www.cccil.org and for information about traumatic brain injury visit www.catbi.org.

"Relearning how to live," San Jose Mercury News

<http://www.mercurynews.net/wishbook/2009/page.php?w=brain>

There had been fires all that summer around South Lake Tahoe, flushing the wild animals from the places they normally grazed into the open. As Aram Attarian and Carol Welsh set out for their Menlo Park home that morning in 1996, the only smudge on a day Welsh remembers as "postcard-perfect" was the layer of smoke that blanketed the horizon.

They had ridden to Tahoe on his motorcycle to celebrate their first wedding anniversary. Aram took pictures of Carol, stretched out on a rock in her biker chick leathers, and one of himself in which he looked exactly like Jack Nicholson in "Easy Rider." As they started back, a life filled with such heedless, carefree mornings stretched out before them like the road ahead. There was no time to get out of the deer's way. The terrified animal hit the Harley-Davidson and ripped it apart like a piñata. Attarian never let go during the bike's sickening slide of several hundred feet. When Welsh, who was badly injured herself, got to her husband, she untangled him from the wreckage with the help of a passing motorist.

Still conscious, Attarian wanted to know what happened. "I told him, 'we hit a deer, but it's all right,'" Welsh recalled. "And then he said, 'What happened?' I thought he didn't hear me, so I said, 'We hit a deer, but it's

OK.' And he said, 'What happened?' And I *knew*. I knew that the person I married was gone."

Attarian had shattered his right shoulder, broken four ribs, punctured a lung and fractured his skull in two places. The accident left him with a traumatic brain injury so debilitating that he couldn't walk, talk or feed himself in the hospital. The first night there, his right carotid artery collapsed, causing a second catastrophic injury to the brain.

"The stroke wiped out the whole thing," Welsh says.

In Attarian's case, "the whole thing" was a genius-level IQ — he was a member of Mensa — and a successful career in sales with Apple, Sun Microsystems and several Silicon Valley startups from 1983 to 1996.

During the early months of his recovery, Attarian was permitted only a dozen visits to speech, occupational and physical therapists before his insurance coverage was used up. "I was frantic that he was languishing at home during the first year, which is a very critical period," Welsh says.

Attarian needed an advocate to battle with insurance companies, someone to get him into the right rehab programs and to take care of his most basic needs. As his wife stepped into all those roles, their relationship shifted. And three years after the accident, even as Carol continued to help with Aram's rehabilitation, their marriage ended.

"From the second we hit the ground, I went into caregiver mode," Welsh says. "And my love changed from romantic to maternal. But I definitely feel this has been a step up, not back. I love him now more than I ever have, and we're best friends. I almost feel guilty about all the gifts that I got from this in terms of building character. Because everything I got from the experience meant that Aram had to lose something."

His most obvious loss was in the area of the brain that handles what neurologists call "executive functions," the logic and sequencing skills that the rest of us use without thinking.

It was only after Welsh discovered the non-profit Services for Brain Injury in San Jose that the picture changed radically, and for the better. There, the center's staff helped him relearn to button a shirt, tie his shoes and socialize with others. Before being exposed to SBI's workplace simulations, Attarian often would stand up and walk out of a room in mid-conversation.

"I was like a different person behaviorally," Attarian says. "When I got out of the hospital and started thinking about going back to work, I realized what I had before had changed. Not gone, but I began to understand my cognitive and physical limitations. And making a lot of money working in high-tech was out of the picture."

As he learned to drive a car again (no more motorcycles!), hold a steady job and forge a new relationship with his girlfriend of six years, Attarian has proved that brain injury isn't an ending — it's the beginning of a whole new journey.

To help others like Aram, SBI would like to enhance its Life Skills Lab, where people can re-master basic tasks using familiar, everyday objects. SBI would like to add a bedroom set, so patients can relearn how to make a bed, fold blankets and sheets and hang clothes in a closet. Wheelchair-safe flooring needs to be installed. The lab also would like to include such household staples as an iron, broom, vacuum, washer and dryer and tool kit. High-tech devices like a handheld text reader are also needed.

"A fully equipped Life Skills Lab, like all SBI programming, is likely to be the only safe place a survivor has to explore and relearn the very basic functioning we take for granted," says Christine Camara, executive director. "Life skills are the foundation for all other learning — and for survivors, particularly, as they begin the crucial process of restoring their humanity." Donations in increments of \$50 will help outfit the lab.

KGET's four-part series, "The Silent Epidemic"

A four-part series produced by KGET-TV describing the consequences of traumatic brain injury and need for specialized medical treatment. Includes segments on private insurance coverage of rehabilitation, recent political and legislative action in support of brain injury treatment, combat related

brain injury as a signature of the Iraq war, and the need for specialized medical treatment for both severe and mild traumatic brain injury.

The Silent Epidemic, part 1:

<http://www.kget.com/mediacenter/local.aspx?videoid=38122@kget.dayport.com&navCatId=5>

The Silent Epidemic, part 2:

<http://www.kget.com/mediacenter/local.aspx?videoid=38132@kget.dayport.com&navCatId=5>

The Silent Epidemic, part 3:

<http://www.kget.com/mediacenter/local.aspx?videoid=38206@kget.dayport.com>

The Silent Epidemic, part 4:

<http://www.kget.com/mediacenter/local.aspx?videoid=38227@kget.dayport.com>

Sample Letters to the Editor:

Santa Cruz Sentinel

Group helps veterans transition back home

On Veterans Day, we pause to remember the sacrifices our brave men and women have made on foreign battlefields. We can't forget that tomorrow, many who fought for our freedom will continue waging a lifelong battle to maintain their own independence here at home. An estimated 225,000 Californians live with a traumatic brain injury, a condition that may affect their vision, speech, motor skills or ability to interact with others at home, in the workplace or in the community. The Central Coast Center for Independent Living, which serves Monterey, Santa Cruz and San Benito

counties, has a message for returning veterans and their families today: We will honor your service with a range of support programs to ease your transition back home and to promote your long-term independence. Veterans and their families can find more information about TBI at www.catbi.org. We salute your service.

Elsa Quezada, Salinas

Times-Standard (Eureka, CA)

What's your brain worth to you? In the Wizard of Oz, the Scarecrow valued a brain above anything else. With so much talk about saving dollars, healthcare reform and the economy, isn't it time that we invest a few pennies and some caution to save our brains? What about that helmet, prevention education, fastening your seatbelt or driving sober? A great investment considering that so little can save so much. The average cost of medical and mental health care for a Traumatic Brain Injury (TBI) is \$4 million to \$5 million. (TBI is a blow to the head causing damage to the brain, or "concussion" in its milder, more temporary form.) The divorce rate is above 80 percent when a spouse sustains a TBI. What's a family and individual counseling program worth to you and your children?

The conk on the head has been an object of comedy for centuries, yet serious conversation about brain injury is often avoided. Reasons for skirting the issue are unclear, yet the prevalence of such injuries is undeniable. Combine the new incidences of spinal cord injury, multiple sclerosis, H.I.V./AIDS, breast cancer and heart attack, multiply that times six and that's how many new TBIs are sustained each year in the U.S. People in rural areas like ours are most prone to brain injuries and TBI is the signature wound of the Iraq/ Afghanistan wars. It's becoming a lot more common to greet a returning soldier or a neighbor who is affected in some

way.

It took a jaunt down the yellow brick road and the length of a story for the Scarecrow to realize that something he already had was worth, well ... everything. When is a good time for you to ask, "What's my brain worth to me?"

Jeffrey Smoller

Making Headway Center for Brain Injury Recovery

Eureka

Summary

This manual provided a variety of helpful tools and resources that can be used and modified to serve consumers with Traumatic Brain Injury and veterans. The manual can also be useful in assisting consumers with other disabilities. It is our hope that it will result in consumers receiving a wider range of accessible services that address the unique needs of people with brain injuries. For more information on TBI in California, please visit www.catbi.org.