So You Wanna Be An Advocate…?

Brain Injury Association of America
8201 Greensboro Drive, Suite 611
McLean, VA 22102
703-761-0750
www.biausa.org

Brain Injury Association

Authors:

Rachel O’Connor

This report was funded with a grant from the Maternal and Child Health Bureau, Health Resources and Services Administration. It does not necessarily reflect the views of the Bureau, HRSA, or the Department of Health and Human Services.
Binder Sections

1. So You Wanna Be an Advocate Overhead Presentation
2. How a Bill Becomes a Law
3. State Legislative Districts Maps
4. Senatorial Districts Maps
5. State Representatives Districts Maps
6. Senators and Representatives
7. State Senate Standing Committees
8. House of Representatives Standing and Statutory Committees
9. The Advocacy Toolbox
10. The Advocacy Toolbox Overhead Presentation
11. Communicating with the Grass Roots
12. Using the Media Effectively
13. Grassroots and Media Overhead Presentation
14. Writing the Script
15. Glossary of Legislative Terms
So You Wanna Be an Advocate

Overhead Presentation
How A Bill Becomes A Law
Learning Goals

1. Participants will be able to describe the process of how a bill becomes a law.

2. Participants will understand the difference between state and federal legislation.

3. Participants will be able to identify their district representatives and senators.

4. Participants will be able to understand the committee process and to identify leaders within it.

5. Participants will be able to identify Majority and Minority party leaders.
Exercises

**Exercise One:** Included in your packets is a bill introduced in your legislature. Review the two documents and see if you can establish the following:

1. Was the bill introduced in the House or the Senate?
2. Who sponsored the bill?
3. What committees was the bill referred to?
4. Who would be some of the key players to focus on for advocacy purposes?

**Exercise Two:** Study and review the three Legislative District maps provided in this manual, then answer the following questions:

1. How many Senators are there in the State Legislature?
2. How many Representatives?
3. Identify and list your state Senator based on the district map, then record their name, phone number and address for later use:
   
   Name: ________________________________________
   Phone number: ________________________________
   Address (District) ______________________________

4. Identify and list your state Representative based on the district map, then record their name, phone number and address for later use:

   Name: ________________________________________
   Phone number: ________________________________
   Address: ______________________________________

**Exercise Four:** Can you identify who is the Majority Party in the House? In the Senate?
State Legislative Districts
Senatorial Districts
State Representatives Districts
Senators and Representatives
State Senate Standing Committees
House of Representatives
Standing and Statutory Committees
The Advocacy Toolbox
Learning Goals

1. Participants will be able to demonstrate successful techniques for advocating for services to meet the needs of persons with brain injuries.

2. Participants will learn the process for delivering testimony for legislative hearings.

3. Participants will learn how to choose a sponsor for legislative efforts.

4. Participants will learn how to meet public officials and discuss issues.
Legislative Advocacy Strategies

Advocating for a change in public policy is interesting and fun. Because we live in a world where time is limited, it is important that you strategize beforehand to insure that your efforts are targeted to make the most impact. When developing a strategy, keep the following tips in mind:

**Cultivate Leadership Support:** It is crucial that you cultivate support from the Majority Party in the legislature. Committee Chairs often have a great deal of power in determining the outcome of legislation, and it is vital that you keep them informed and that you rally constituents who can impact them. Be a careful observer and cultivate relationships with informal leaders as well.

**Use Constituents Wisely:** Voting constituents make the most impact on legislators. Once you have identified the leaders, be sure to identify four or five constituents within their respective districts who can make calls or visits on behalf of your efforts.

**Know Your Opposition:** If you are advocating for a change in law or a controversial bill, understand who will be opposed to your legislation and work for compromise. Be sure your sponsor is aware of anyone who might present public opposition. Understand and try to find counter points for opposing testimony.

**Know Your Friends:** Other disability and health related groups would probably be willing to assist you in your efforts. Be sure to keep them informed and involved.

**Advocate All Year Long:** A strong, well-planned grass roots advocacy effort can greatly reduce the time you need to spend at the Capitol. Try to motivate constituents to get the message out before the legislature starts and reduce the actual time you need to be present during the legislative session. Building strong working relationships with Executive State agencies may also lead to positive systems change.

**Get To Know Legislative Staff:** Legislators usually have assistants, and generally Legislative Committees have a host of staff at their service. Assistants are generally responsible for overseeing legislators appointment books, answering telephone calls, and opening mail. Committee assistants often keep minutes of meetings, prepare reports, and sometimes offer key advice. Generally staff serves as confidantes to the legislator and can provide you with key information such as when your bill is scheduled. It is important that you build a working relationship with staff, or at the least introduce yourself and make yourself available should they need to contact your regarding a bill or other issue.
Choosing a Sponsor Wisely

One of the most important decisions you will make is choosing a primary sponsor for your bill. Your primary sponsor will take the lead responsibility for making sure your bill gets through the legislative process, and ultimately is signed into law. A bill may have up to four co-sponsors. In choosing a primary sponsor, you will want to consider a legislator who:

- Is a member of the majority caucus.
- Is committed to the issues that your bill addresses.
- Has seniority or some influence or power within the legislative process.
- Has and commits to the time necessary to insure passage.
- Gets along well with others.
- Has a track record of success.

Once you have identified a possible sponsor, you will want to make an appointment with him/her to discuss the proposed bill. If you are representing an organization, no more than three or four representatives should visit as a group. Each person should be prepared to advocate from his/her position. Covered issues include:

- Describe why the bill is necessary and how it will change the current law if it does.
- Be candid about any anticipated opposition, including the any state agency opposition.
- Describe the ways that you are available to help with the bill during the session. This includes providing testimony, getting others to testify, and building a constituency of support to make visits, phone calls and write letters.
- Assist in choosing co-sponsors wisely, preferably members of committees you are likely to encounter.
- Be sure to leave a copy of the bill.
Communicating With Legislators

Whether you are a professional or volunteer advocate, it is vitally important that you communicate in a clear and professional manner to get your point across. Below are some basic guidelines for communication, followed by some methods for impacting legislators.

Personal Visits

Face to face visits are one of the most effective ways to influence legislators. Legislators have offices in the state capitol during the session, but often you can arrange visits with them at their district offices when the legislature is not in session. This is often preferred since seeing a legislator during a busy session may be difficult. In addition, meeting in a more private setting often leads to a candid, in-depth discussion of the issues.

It is always best to call first to make an appointment. Remember that every constituent has both a Senator and a Representative, and try to meet with both of them. If you cannot get an appointment, ask to meet with key staff members. The following are recommendations for visit with legislators:

**Know That You Are The Expert:** Legislators are generalists and often do not have in-depth knowledge about specific issues. Assume you know more about the topic you are discussing than does a legislator.

**Be On Time:** Make an appointment and be on time. Remember that legislators often are not; they may be in a meeting or hearing and cannot anticipate an end time.

**Small Groups Are Ok:** Three to four persons are optimal; don’t overwhelm a legislator with a large group.

**Be Brief:** Legislators are busy people. Try to plan your discussion so that it lasts from 5-10 minutes.
**Leave A Fact Sheet:** Legislators are more inclined to read summarized materials. Make a one-page fact sheet to leave with the legislator.

**Be Prepared:** Practice summarizing in three-minute increments hitting on the high points. Know your issue. If you are coming to speak about specific legislation, know the bill number and sponsor and bring a copy of the bill.

**Begin By Telling Who You Are:** Be sure to state if you are a constituent.

**Be Clear On What You Want:** Ask for a specific vote or action.

**Be Nice:** Don’t blow your cool no matter how hot you might get. There’s always a next time.

---

**Contact By Phone**

All legislators have office phone numbers, and some freely publish their phone numbers in local directories. Even if the legislator is not in his office, you should speak to his/her Legislative Assistant. The Legislative Assistant will faithfully pass along any message you have. When you call:

**Identify Yourself:** You might begin by saying, "This is Jane Doe calling from Any Town about xyz."

**Ask For Someone To Speak To:** Ask to speak to the aide who deals with the issue about which you're calling.

**Leave A Message:** Be sure to state what you're calling about. Leave a bill number if you are calling about specific legislation.

**Ask For A Response:** Ask for a written response to your request.

**Don’t Be Intimidated:** You're a concerned citizen; you don't have to be an expert.
Contact by Mail

When You Write:

**Be Personal:** The more personal your letter is, the more influence it has, particularly if you are a constituent. Say what's on your mind and in your heart. Use your own words; you don’t need to write like an expert to have influence. Describe briefly how the legislation in question affects you personally or affects people where you live.

**Handwrite:** Handwrite your letter if your handwriting is legible. Handwritten letters are now the only way that the recipient knows that the letter really comes from an individual. If you prefer to type a letter, make sure you sign it with a handwritten postscript.

**Be Clear:** Be brief, clear and specific. Stick to one page if possible.

**State Your Reasons:** Begin by stating the reasons for your letter. Then write about your personal concerns and experiences and add any information you may have supporting your opinion. For example, if this legislation would make it possible for you to…. then say so!

**Make A Request:** Close with a specific request - that the policy-maker state his or her position in a letter to you, that he or she vote in a particular way - or make a strong summary statement. If you are requesting action on a specific piece of legislation, be sure to include the bill number and the sponsor.

**Be Nice:** Be courteous and reasonable. Show respect for the people you contact, even when you disagree with them. You may be on the same side next time.

**Leave Your Address And Phone Number:** Include your address on your letter. An envelope can get lost.

**Include A Fact Sheet:** Legislators are most apt to read material that is concise. If you have statistics or facts that support your cause, be sure to include them on a one-page fact sheet enclosed with your letter.
Contact by E-mail and Fax

The Legislature is slowly moving into the realm of electronic communications, and many legislators have established Internet addresses. Avoid faxes to legislators and the administration. Many legislators find faxes intrusive and prefer letters that arrive by mail. Faxes may be appropriate if there is an urgent action or a last-minute vote.

- Before you e-mail a legislative or administrative office, call to confirm the address and ask if e-mail is checked daily. Also ask for a response to your message once it has been received. Use e-mail only when you are sure the decision-makers you are targeting are reading and responding to the messages.
If you are introducing a bill, your bill will be first introduced on the floor of the initiating chamber and will be referred for public hearings in committees. If you are taking a position on legislation, you will want to be present to provide testimony. The first time a citizen testifies before a legislative committee can be somewhat intimidating. Here are some tips for making your testimony more effective:

**Follow Protocol:** The proper way to begin your comments is Mister Chairman, Members of Committee, for the record my name is _________, and proceed from there. Follow by introducing yourself and what your interest is in the pending legislation. Knowing this protocol from the onset gives the impression that you know what you're doing!

**Choose Wisely:** Testimony can be an important part of presenting a bill, and careful consideration should be given as to how witnesses are selected. Do not swamp a friendly committee with too many witnesses.

**Be Representative:** Try to choose witnesses who represent different perspectives. Self advocates, professionals and family members should all be represented. Try not to have duplicate testimony. Anecdotal testimony by a person who has experienced the condition can be particularly compelling.

**Be Timely:** Show up early, or at the very least, be on time. The chairperson may re-arrange the posted schedule.

**Sign Up:** As soon as you arrive, place your name on the sheet for the bill or bills you are interested in. If you wish to testify, there is a place for you to indicate so. If you don't sign the sheet, you won't be called to testify.

**Get the Word Out:** When called, go to the front table and sit down. If you have written testimony to distribute to members, it should be given to the committee staff to distribute. Pull the microphone to within four or five inches from your mouth so the members can hear you.

**Be Brief:** Testimony should be kept brief (5-10 minutes). Be prepared, however, to shorten your remarks to three minutes if the chair has set such a limit.

---

So You Wanna Be An Advocate...? • Brain Injury Association of America • 2001 • www.biausa.org • (703) 761-0750
**Leave Copies:** If you’ve written your testimony, be sure to give copies to all committee members and leave copies with the committee aide.

**Be Nice:** Even if you are very angry, be respectful and calm in your remarks to the committee. To do otherwise will damage your credibility and your impact.

**Commit To Finding Answers:** If committee members have questions that you cannot answer, admit this and commit to finding the answer and getting back with the member. Then be sure and do it!

**Say Thanks:** When you finish your remarks, thank the committee for their attention and invite any questions they might have.

**Follow Up:** Listen carefully to all discussion and follow up if there are any unresolved questions or issues.
Working Within the Executive Branch

The Executive Branch of Government includes all state agencies and the Office of the Governor. Whether you are advocating for a change in policy or contemplating introducing a bill, it is important to remember that the Executive Branch plays an important part in public policy.

If you are advocating for increased services, it is important to remember that most states require that public funding be administered by a state agency. In seeking to change laws or increase services through public allocations, it is vital that you meet with state officials who will be administering services or who are impacted by changes in public policy. In most states this is the Department of Health, Human Services or Department of Vocational Rehabilitation.

Part of your advocacy effort should include meeting with the Governor’s office to obtain support, or at the very least, meeting with his/her staff. Some tips for working successfully with the Executive branch include the following:

- If you are seeking an increase in funding or a change in services, meet with the appropriate state agency to determine if it would be supportive of the measure. If they ARE supportive, you may want to ask them if they would wish to initiate an increase in service dollars through the Executive budget. Be sure to bring informational material such as fact sheets.

- Internal agencies, such as Governor’s Councils on Disability, can be important advocacy bodies and potential allies. Be sure to meet with them regarding your efforts.

- Many state agencies are restricted in ways that they are able to impact legislation. Some have more leeway. Be sure to ask your state officials their formal position on your proposed legislation.

- Some state agencies provide forums and public hearing processes to determine priorities. If you are introducing legislation, stay informed about the hearing process and ask that your proposed legislation be made an agency or department priority.

- Impact the Office of the Governor in any way possible so as to avoid a veto. If you have a supportive state department, ask them to assist you in obtaining Gubernatorial support.

- Keep continuous grassroots support focused on a Governor who is ambiguous.
Tips for the Serious Advocate

Make Friends In High Places: Take the time to understand who the leaders are within the legislative session. Usually this means the floor leaders from both chambers and the committee leadership. Insure that you have constituents from their districts approach them for support early on in your venture.

Target Your Efforts: If you study the committee listings you can generally predict the committee referrals your bill will receive. Try to cultivate one leader in each committee who will take the lead in supporting your efforts. Target your grass roots effort to see that each committee member has committed to voting for your bill before it is scheduled; it will decrease stress and a smooth ride for a “do pass” when your bill is heard.

Get Your Bill In Early: The legislative session is a race from start to finish, and many bills barely make it out of the starting gate. Try to see that your bill is introduced early in the session to assure it doesn’t die unheard.

Don’t Leave Your Bill Unattended: Unattended bills have a way of disappearing overnight. Be sure to track your bill from committee to committee to insure that it receives the proper treatment.

Track Bill Analysis: Your bill will be analyzed a number of times throughout the legislative process. Ask staff where you can get a copy and be sure that the information is correct. Better yet, drop a copy of a fact sheet off with staff analysts from the majority and minority who will appreciate your effort to make their job easier.

Go For A Test Run: Most legislatures have Health and Human Services Interim Committees that establish priorities for the upcoming legislative sessions. Find out who is the chair of yours and see if you can present your idea as a test run for the upcoming session. Be bold and ask that the interim committee make it a priority item in the upcoming session; the worst they can do is say no.

Create A Script: Legislators enjoy being knowledgeable about issues and asking questions that are sure to generate interesting discussion. If you know what committees your bill is scheduled to be heard in, create a list of smart questions and ask a friendly committee member to use it to promote enhanced discussion. In addition, ask your sponsor if he/she would like you to develop a short script with talking points to assist him/her in introducing your bill.
Build Relationships With Other Advocates: The Capitol Building is full of advocates; some with agendas similar to yours. Other advocates with similar interests may be willing to take time to share experiences and insight with you. In addition, they may have a vested interest in your bill and may assist or mentor you in your efforts. Some advocates you might look out for are ones that represent the following:

- State Hospital Associations
- Hospitals and Rehabilitation Facilities
- Health Maintenance Organizations (HMO’s)
- Mothers Against Drunk Driving
- The Arc
- Independent Living Centers
- Insurance Companies
Exercises

**Exercise One:** Suppose the Brain Injury Association decided to introduce a bicycle helmet law during the upcoming legislative session. You decide you would like to advocate for the bill. What sort of facts would you include in a letter to your legislator?

**Exercise Two:** Suppose the Brain Injury Association asked you to assist them to find persons to testify on behalf of a funding bill to increase services to persons with brain injuries. Who do you think would be good to testify on behalf of the bill? What would you ask him/her to say? Why?
Samples
Sample Letter on Patients' Rights

The Honorable {First and Last Name}
PO Box 40600
Olympia, WA 98504-0600

Dear Senator {_______}:

I am deeply concerned about medical care for people with brain injury {describe your particular relationship with brain injury, family member, BIA affiliate employee or volunteer, etc.} I urge you to support a Patients' Bill of Rights that includes the following principles:

Medical Necessity:
- Protect the patient-physician relationship
- No arbitrary limit on covered services
- Treatment decisions based on standards of medical practice
- Access to drugs when patients need them

Access to Specialty Care:
- Protect the special needs children and adults with brain injury
- Special expertise for special health concerns
- Simplify access to specialists for patients who are seriously ill
- Access to clinical trials when no standard treatment is effective

Accountability:
- Allow doctors to tell patients about all treatment options
- Encourage doctors to provide the best care, rather than allow plans to provide incentives for doctors to limit care
- Give patients opportunities, both internally and externally, to appeal denials of service and voice concerns about their plans
- Allow patients to use the appeals process without fear of plan retaliation
- Allow providers to advocate for their patients without retaliation

Continuity of Care:
- Protect patients against disruptions in care due to a change in plan or a change in a provider's network.

Persons with brain injury can require a wide range of health care services, from the acute trauma setting, to the emergency room, to the intensive care unit, to various rehabilitation programs and long-term services in the community. The needs of people with brain injury are unique to each individual.

BIA strongly supports a Patients Bill of Rights that allows persons with brain injury to access emergency care and basic health care services, as well as neurologists, neuropsychologists, psychiatrists, physical, occupational and speech/language therapists, mental health services,
durable medical equipment, assistive technology, prescription drugs and rehabilitation services deemed appropriate by qualified doctors.

Persons with brain injury may require such health care services for significant periods of time after injury. In some cases, long term rehabilitation and assistance is needed to return to one's work, family and the community.

Senator, the need for action on substantive managed care legislation is great. In the United States today, there are 5.3 million persons with long-term severe disability as a result of brain injury, and 6.5 million persons with some form of injury. Because of the sophistication of our medical technology, more and more individuals are living with brain injury and overcoming what used to be insurmountable secondary injuries. Our health insurers need to recognize that persons with brain injury have unique needs that if met, would allow millions of Americans to lead full and productive lives.

{Insert a few words about your personal interest or special needs here.)

Please do the right thing and support a substantive Patients' Bill of Rights. Thank you for your quick action on this critical issue.

Sincerely,

Your name
Sample Letter

The Honorable {Your Representative's Name Here}  March 23, 2000
U.S. House of Representatives
Washington, D.C. 20510

Dear Representative {Your Representative's Name Here}:

I appreciate the support you have provided in the past to programs for people with traumatic brain injury (TBI). {You may want to include your personal connection to the issue here.}

Today, according to the Centers for Disease Control and Prevention, traumatic brain injury is the number one killer and cause of disability of young people in the United States. Motor vehicle crashes, sports injuries, falls, and violence are the major causes of traumatic brain injury. TBI can strike anyone -- infant, youth or elderly person -- without warning, and often with devastating consequences. Traumatic brain injury affects the whole family and often results in huge medical and rehabilitation expenses over a lifetime.

More than 2 million Americans every year sustain a traumatic brain injury, and there are more than 5.3 million people in our country today living with disabilities that result from brain injuries. Brain injury causes death and disability most of all among young people in the prime of their lives who should have decades of potential and productivity ahead of them.

The single piece of legislation passed by the US Congress specifically to address the issues faced by people with traumatic brain injury is the Traumatic Brain Injury Act of 1996. As stated in the legislation itself, the Act was passed by Congress “to expand efforts to identify methods of preventing traumatic brain injury; expand biomedical research efforts or minimize the severity of dysfunction as a result of such an injury; and to improve the delivery and quality of services through State demonstration projects.”

Over the past three years, the TBI Act has provided essential and successful programs that have advanced research, knowledge and awareness, as well as treatment and services, to people who are living with brain injury. Much remains to be done, however, to address this pressing public health problem, this silent epidemic that compounds every year, but about which still little is known. The Traumatic Brain Injury Act is currently in the process of reauthorization.

Today, on behalf of the 5.3 million Americans living with brain injury and their families, I am asking you in your capacity as a member of the Appropriations Sub-Committee on Labor, Health and Human Services, Education, and Related Agencies to request $25 million in FY 2001 appropriations to fund the Traumatic Brain Injury Act. The requested appropriations are delineated as follows:

- $6 million for the Centers for Disease Control and Prevention (CDC) for surveillance so that we can continue to learn the incidence and prevalence of brain injury in the U.S. population
$9 million for the Health Resources Services Administration (HRSA) for grants to states for demonstration projects to improve access to health care and other services for people living with traumatic brain injury and their families

$5 million for applied research at the National Institute on Disability and Rehabilitation Research (NIDRR)

$5 million for the Department of Health and Human Services to include people with traumatic brain injury as beneficiaries of the state Protection and Advocacy Systems.

Again, I appreciate your ongoing support for traumatic brain injury programs, and am willing to assist you in any way possible.

If you have questions or comments regarding this request, or any other issue related to traumatic brain injury, please do not hesitate to contact me or the Brain Injury Association's Public Policy Department at 703-236-6000.

Sincerely,

{Your Name Here}
{Your address and phone number here}
Crashes Injuries Aren't Accidents

In the state of Washington in 1999 the Washington Traffic Safety Commission reported that there were 635 traffic deaths. This translates into an additional 12,065 Washingtonians hospitalized for injury and 190,500 injuries that required medical attention.

Traffic crashes are a leading cause of death in the United States and the leading cause of traumatic brain injury.

Wearing seat belts is the easiest and most effective way of cutting the highway death and injury toll, and strong occupant protection laws are the most effective way of increasing safety belt use.

Traffic crashes aren't "accidents." They are both predictable and preventable. The quickest, easiest, and most effective way to prevent traffic injuries and fatalities is to make certain that every vehicle occupant is properly buckled up on every trip.

Washington's current seat belt law is a secondary enforcement law. This means that law enforcement officers are allowed to write a seat belt law citation only when other offenses are also committed. The National Highway Traffic Safety Administration estimates that states that have primary safety belt laws typically have significantly higher seat belt usage. Under primary enforcement, a citation can be written whenever a law enforcement officer observes an unbelted driver or passenger.

According to traffic safety advocates changing to a primary seat belt law in the state of Washington would save 111 lives per year. In addition, the change would result in an estimated 2,000 fewer hospitalizations for traffic related injuries AND over 33,000 fewer injuries requiring medical attention. Without doubt many fewer people would experience the disabling effects of brain injury! In fact of ALL the causes of brain injury this one change would have the largest impact to reduce the incidence of traumatic brain injury in the state of Washington!
Last year legislation was introduced to the Washington legislature to make the seat belt law a primary law. The bill failed to pass. However, work continues with grassroots coalitions and law enforcement agencies.

Traffic injuries are the leading cause of injury deaths and the leading cause of all deaths for people ages 6 to 27. They also are the leading cause of on-the-job fatalities and the third leading cause of death for all Americans; only cancer and heart attacks claim more American lives. However, far more people are injured and survive motor vehicle crashes than die in these crashes. In the US in 1995, for example, while almost 41,800 persons were killed in traffic crashes, over 3.4 million injuries were documented in police-reported crashes.

Every 14 seconds someone in America is injured in a traffic crash and every 12 minutes someone is killed. When a traffic crash occurs, occupants are still traveling at the vehicle's original speed at the moment of impact. Just after the vehicle rapidly comes to a complete stop, unbelted occupants slam into the steering wheel, windshield, or other parts of the vehicle's interior. Seat belts are effective in reducing fatalities and injuries caused by this second collision, or "human collision," when the vehicle's occupants hit some part of the vehicle interior or other occupants. Seat belts provide the greatest protection against occupant ejection. In fatal crashes in 1995, only two percent of restrained passenger car occupants were ejected, compared to 25 percent of unrestrained occupants. Ejection from a vehicle is one of the most injurious events that can happen to a person in a crash. Three-quarters of the occupants who are ejected from passenger cars are killed.

Please support our efforts to reduce the incidence of brain injury by passing a Primary Seat belt law in the state of Washington.

For further information
Please Call the Brain Injury Association of Washington.
16315 N.E. 87th Street, Suite B-4
Redmond, WA 98052
Phone: (800) 523-LIFT
Fax: (425) 895-0458
Email: biawa@biawa.org
Website: www.biawa.org
Sample Disability Related Questions to Presidential Candidates

August 21, 2000

1. Do you plan to have an individual or group of people work on your transition team with the specific task of dealing with disability issues, in particular disability policy and the recruitment of qualified individuals with disabilities and disability experts to join your Administration?

2. What would you do in the first 100 days in office to signal to the disability community that you consider us a core constituency and that your Administration intends to work with us to improve the lives of 54 million children and adults with disabilities in the U.S.?

3. How do you plan to handle the coordination of disability issues in the White House?

4. Do you support full enforcement and implementation of the Americans with Disabilities Act, the Individuals with Disabilities Education Act and the Fair Housing Act and what strategies would you pursue as President to strengthen the impact of these laws?

5. How will your Administration address the astoundingly high unemployment rate for people with disabilities?

6. What specific steps would you take to ensure the long-term solvency of Social Security while you take into consideration the disability programs within Social Security?

7. What is your position on expanding home and community based long-term services and supports (as opposed to institutions and nursing homes) for people with disabilities and on assisting family care givers?

8. How will your policies on health care (e.g. basic reforms, patients’ bill of rights, prescription drugs, etc.) impact on people with disabilities?

9. What is your position to ensure that people with disabilities have access to decent, safe, affordable and accessible housing in the community through HUD programs?

10. To what extent will the Supreme Court’s consideration of key disability rights laws like the Americans with Disabilities Act and the Individuals with Disabilities Education Act influence your nominations to the court?

11. How does your Administration intend to establish ongoing dialogue with the disability community?
ADDRESS: Madame Chair, members of the Committee, my name is Rachel O’Connor, and I am the Regional Director of the South Central Region of the Brain Injury Association, Inc. The South Central Region is comprised of the State of Missouri and nine additional states, including Arizona, Nevada, New Mexico, Texas, Louisiana, Arkansas, Oklahoma, Nebraska, and Kansas. I live and work out of my home state of New Mexico. I was invited here today by the Brain Injury Association of Missouri to speak about how other states are developing systems of services for persons with brain injuries, and to provide you with information regarding the development of long term care services including TBI Medicaid Waivers and TBI Trust Funds.

Prior to beginning my testimony, I would like to thank you for being present here today and for listening to the concerns and recommendations of the brain injury community regarding the development and provision of services to persons with brain injury in the State of Missouri.

INTRODUCTION: The national Brain Injury Association is a nonprofit organization devoted to the development of strong State and Federal programs to serve persons with brain injuries. We are centrally located in Washington, DC, and have 44 State Affiliate Associations located in various states across the Country. The mission of our organization is to “Create a better future through brain injury prevention, research, education and advocacy.” Regional Directors, such as myself, are located across the country to assist state brain injury associations in working with States to develop strong systems to serve persons with brain injury.

I would like to start my testimony today by speaking about the core components that are being used by states across the country to begin to serve persons with brain injuries. Following that, I would like to speak specifically to the development of services in the State of Missouri, followed by some suggestions for your consideration. I will provide my testimony for you in writing and am available to answer any questions you might have either today or at any time in the weeks or months following your hearings.
**State Systems:** The Brain Injury Association, Inc. is committed to the development of strong, viable systems to serve persons with brain injuries. This is a relatively new movement. Prior to the 1960’s, and the development of a rapid emergency transport system during Vietnam, most persons who sustained severe traumatic injuries did not survive. Today, thanks to the development of the EMS system and other advanced in technology and medicine, many persons with brain injuries are not only surviving, but also leading active lives within their respective communities. In the 1970s, the TBI death rate was 50%; today it is about 22 %.

In 1996 the US Congress passed the first piece of significant Federal Legislation, the Traumatic Brain Injury Act, to assist states in developing services for persons with brain injuries. As a result of that legislation, the Centers for Disease Control conducted surveillance studies to determine the national incidence and prevalence of persons with brain injuries. Some significant findings included the following:

- Currently there are 5.3 million Americans living with a TBI
- 1.5 million people sustain a brain injury each year and approximately 5,000 a year are injured in Missouri
- One Million a year seek emergency care
- 230,000 a year are hospitalized
- 50,000 a year die
- 80,000 a year have a long term disability

Despite the large numbers, persons with brain injury lack access to publicly funded services that are traditionally being used to serve persons with disabilities in our country. Persons with brain injuries are largely ineligible to receive services within either the developmental disability or mental health services systems. When they are eligible, the services are often not meaningful in fostering independence. Studies show that although the brain injury community is growing in both numbers and political organization, public spending for persons with developmental disabilities totals nearly $15.5 billion dollars to serve 650,000 persons with developmental disabilities, while public spending for persons with brain injuries is limited to $226.5 million to serve 38,357 persons with brain injuries. In comparison - persons with TBI receive less than one percent of the national financial support compared to people with developmental disabilities, despite the fact that the CDC has estimated that the population of persons with brain injury totals 5.3 million and persons with developmental disabilities total 7.2 million. Persons with brain injuries continue to be underserved, particularly in the area of long term care.

Many states, however, are beginning to build infrastructure and devote dollars to serving persons with brain injury. In assessing the development of states and in working within States in the Brain Injury Association South Central Region, I use six core components to assess the development of States. The six core components include the following:

- **TBI Registry:** How many persons are injured, what are their demographics, and what are the implications for prevention strategies?
- **HRSA Grants:** Has the State pursued monies available to build infrastructure through Federal funding made available to states?
Box 1

Advisory Council: Has the State committed dollars to a Governor appointed Council to direct and advise on policy?

Trust Funds: Does the State have a TBI trust fund, or has it devoted state dollars to services?

TBI Home and Community Based Medicaid Waiver: Does the State have a long term care waiver funded by Medicaid?

Dedicated State Office: Has a State agency taken the lead in the development of services, and are full-time employees devoted to serving this population?

The State of Missouri: The Brain Injury Association South Central Region is comprised of ten States, including the State of Missouri. Within this region states are in varying degrees of development with regard to both infrastructure and the development of services. The State of Missouri has developed in a manner that is unique. Missouri is an established leader in the development of infrastructure, but it has been less responsive in service delivery. Problematic issues noted by consumers, family members and professionals within the State of Missouri include the following:

Alternatives to institutionalization for persons with brain injury are inadequate.
Long term care services in Missouri largely exclude persons with brain injury
Few dollars are available within the system to serve persons with brain injury.
Areas of particular concern identified by Missouri advocates include: housing, transportation, transitional services, and behavioral management.

The State of Missouri is perhaps the most developed in terms of systems capacity within the South Central Region. The Missouri Brain Injury Advisory Council has been a longstanding voice for persons with brain injury, both within this state and across the country. Missouri was one of the first states to apply for and receive Federal TBI Act monies through an implementation grant with the Health Resources Services Administration. The State Department of Health has taken the lead in the provision of services, and Missouri has reliable numbers through a TBI Registry. State services are also augmented by the presence of the BIA of Missouri, which serves as a strong and active voice in many areas of the state for the people with brain injuries, their families, and the professional community.

Despite this however, the State of Missouri has dedicated relatively few dollars to the actual provision of services, particularly long term care services, for this population. The State has allocated $570,000 in general funds to provide a variety of services. Additional monies, approximating $350,000, have been appropriated for the development of a system of Service Coordinators. In comparison, other states within this region have allocated more extensive service dollars:

Texas: $8.7 Million
Kansas: $5.0 Million
Louisiana: $2.5 Million
New Mexico: $2.0 Million

So You Wanna Be An Advocate...?  •  Brain Injury Association of America  •  2001  •  www.biausa.org  •  (703) 761-0750
**Recommendations and Conclusions:**  Long Term Care Services for persons with disabilities are typically provided in the form of some combination of Medicaid Waiver Services and/or state general funded services. Many states have moved forward in serving persons with two systems, Trust Fund monies to provide interim/gap or emergency funding and Medicaid TBI Waivers.

**TBI Medicaid Waivers:** Traditionally persons with disabilities, in particular persons with DD/MR, have received long-term care services through Medicaid Waivers. In response to the issues posed by persons with brain injuries being ineligible for DD and other services, the Health Care Financing Authority (HCFA) responded by developing a model Home and Community Based Service Waiver for TBI. The first TBI waiver was developed in the State of Kansas, and now 25 States have TBI Waivers in place. Waivers maximize available funds by providing a federal match for dollars, and often serve as an alternative to costly and inappropriate institutionalization. In addition, they generally serve the most severely injured and are geared towards maximizing independent living.

Medicaid offers a number of options in services and most states offer a different array. Core services often available for persons with brain injuries through Waivers Services include but are not limited to:

- Case Management
- Homemaker
- Personal Care
- Habilitation and Therapies
- Family Training
- Adult Day Treatment
- Respite
- Life Skills Training
- Behavioral Programming
- Assistive Technology
- Skilled nursing
- Supported Employment
- Alcohol and Drug Counseling

The Brain Injury Association, Inc. considers a brain injury waiver one of the key components of a strong state commitment to individuals with brain injury, and recommends that the State of Missouri give consideration to the submission of a proposal for waiver services to HCFA. While Waivers may serve only a small portion of the brain injury population, they are crucial to the quality of life of for those served. In addition to having met the needs of the most severely injured, states benefit by maximizing state dollars and by reducing the need for institutionalization. Communities benefit as well as individuals who often regain skills for independent living and retain ties to family and friends.
**Trust Funds:** Currently 15 States across the country have in place state TBI Trust Funds. Within the South Central Region, the States of New Mexico, Louisiana, Texas, and Arizona currently have trusts funds, and the States of Nebraska and Kansas are currently pursuing legislative efforts toward developing them. TBI Trust Funds are a dedicated funding stream used to serve this population, and are generated by a host of methods, some examples that include:

- Adding of surcharges on DWI/DUI
- Surcharges on seatbelt violation
- Adding of fees and fines on State issued tickets for moving violations
- Adding of fees and fines on driver’s licenses
- The use of tobacco settlement monies

Trust funds can generate significant amounts of monies, which are generally allocated by courts and other systems to the lead State Agency for disbursement to persons and families in need. Funds across the country generate varied amounts of funding. The State of Florida raises $13 million a year through trust funds, the State of New Mexico raises $1.6 million, and the State of Texas raises about $8 million. Funds are often used to fill gaps or for emergency care and are capped both in duration of availability and amount allocated. For example, New Mexico created the Brain Injury Services fund by adding a $5 fee to state issued tickets. Funds are available for a host of services including rehabilitation, case management, medications, assistive technologies, therapies, emergency housing and a variety of other services. Funds are short term in duration and may not exceed three years with a lifetime limit of $75,000. Other states have instated similar restrictions.

Trust funds are valuable to states for a number of reasons:

- Approximately 50% of TBI’s are due to motor vehicle crashes so there becomes a degree of accountability of high-risk drivers to support those injured.
- They provide short term funding necessary until recipient is on long term care services.
- They can often prevent complete financial devastation, homelessness and/or crisis.
- A small investment by the State may prevent more costly institutionalization and prevent the decay of the family.

Some states may have constitutional issues with regard to the use of fees and fines and must pursue additional legislative and/or modifications to address this issue. It is important to note that state BIA’s, most recently the BIA of Georgia, have successfully passed both trust fund legislation and accompanying constitutional amendments. Trust funds that are not generated through fines, notably the tobacco settlement monies, do not require any change to the constitution.
**Recommendations:** The State of Missouri has served as a leader in the South Central Region in the development of infrastructure to serve persons with brain injury within the public system. Given the nature of the waiting list and HFCA's current receptiveness towards TBI Waivers to serve this population, the Brain Injury Association urges you to consider allocating state general fund monies to be matched by Federal monies for a TBI Waiver. We believe that this investment would decrease the number of institutional placements in your State and would lead to the development of a strong community based system geared towards maximizing the independence of persons with brain injury.

In addition, the National association would urge your consideration of the development of a Trust Fund to increase the availability of state committed dollars to serve this population. Trust funds serve a valuable purpose to persons as a short term or crisis solution that may alleviate a more costly solution at a later date. Trust funds also offer flexibility in problem solving that is not available through Medicaid or other funding.

We request that both efforts supplement, not supplant, current state efforts. The State has done an admirable job in creating a system of service coordinators, and it is vital that these systems remain in place.

**Final Note:** Attached to my testimony is a summary of states that have pursued Medicaid Waivers, as well as the services they offer. In addition, I have provided a summary to you of Trust Funds that are currently in place in 15 states. If you have any questions regarding this testimony, or the attached information, I am available to answer any questions either today or at my office in Santa Fe, New Mexico at (505) 474-3583.

Thank you.
Advocacy Toolbox

Overhead Presentation
Communicating with the Grass Roots
Learning Goals

1. Participants will be able to develop systematic means of communicating with local volunteers who have agreed to contact legislators.

2. Participants will be able to understand the merits of working within coalitions to further advocacy efforts.

3. Participants will be able to identify strategies for communicating with the grass roots
Utilizing the Grass Roots in Advocacy Efforts

“All politics is local”— Thomas “Tip” O’Neill

So What Are Grass Roots Anyway?

The importance of grass roots programs has grown tremendously. Almost every major association or group seeking to achieve a legislative goal undertakes extensive grass roots efforts.

The days are long gone when crucial legislative decisions were made by a few key legislators meeting with advocates behind closed doors in "smoke filled rooms." Today, legislators base most of their decisions on what they hear from their constituents. Those groups able to generate large-scale grass roots pressure are the most effective at implementing their legislative agenda.

So, what is a grass roots program? What are grass roots activities and what impact do they have on legislators?

- A grass roots program seeks to convince elected officials that there is significant local constituent support for a given policy objective. Elected officials care about what their constituents think, especially those who take the time to communicate their views. Lawmakers need the votes of their constituents to get re-elected.

- Grass roots efforts may involve all or some of the following activities aimed at educating elected officials:
  
  - One-on-one and small group meetings with legislators. Meetings can be scheduled at the lawmaker’s district or their Capitol office.
  
  - Generating large numbers of letters and/or phone calls to the lawmaker. This demonstrates mass support for the policy objective.
  
  - Phone calls and letters from influential constituents. These constituents can be personal friends, political supporters, major employers or other influential members of leaders of the community.
• Informal contact with a legislator at social gatherings like political events, town meetings, and fundraisers.

• Generating favorable media coverage such as news stories, editorials, and letters to the editor from leaders of business, professional and civic groups.

• A successful grass roots program mobilizes both a "high quality" and a "significant quantity" of support. This shows lawmakers that:

  • Influential constituents care a great deal about the issue.

  • A significant cross section of the community and a large number of voters support the issue.
Coalition Building

Major advocacy efforts require organization on the grass roots level. An organized campaign will require mobilizing the greatest participation possible from both groups and individuals. Coalitions are useful and have potential for enormous influence in public policy and advocacy efforts.

If you are considering a major piece of legislation, consider developing a coalition to assist in the efforts. A coalition is a group of people and organizations that agree to work together to achieve a particular policy goal. Potential members could include:

- People with brain injury
- Family members of persons with brain injury
- Professionals in the field of brain injury including:
  - Rehab professionals
  - Providers
  - Professionals from the medical field
  - Advocacy/Organizations who serve persons with disabilities
  - Representation from State Agencies
  - Other health and disability related organizations.

Coalitions can serve a variety of needs. They can oversee field services, or “operations” by recruiting new members, setting up speakers bureaus; conducting petition drives, organizing letter-writing campaigns, or overseeing media activity. They can develop budgets and raise monies for campaign events and activities, or generate monies for materials to cover costs of an effective public relations campaign. They can work actively to generate potential support from the general public or policymakers. They can assist in organizational efforts such as developing fact sheets or information, or communication networks to reach volunteers in a systematic and organized manner.
Phoning and Phone Trees

Communicating with the grass roots is vital in any advocacy efforts. As such, phone trees are one effective way of communicating quickly and easily with volunteers and supporter. A phone tree is a system in which some of the phoning gets done by people who get phoned, with the message getting passed along based on some pre-arranged hierarchy.

It's really helpful to set up a phone tree if your list is of good size and you'll need to phone it repeatedly. Phone trees are quick and cheap, and the work is distributed. Call the people and groups on your group's volunteer or supporter lists. Other organizations may also provide you with their lists. If you don't need a live communication, it goes much faster if you make calls when you expect to get an answering machine. There are lots of ways to set them up, but here are some key points:

- The more dependable people should be near the start (the "trunk" or "root") of the tree, and everyone should know that their role is very important, since an unreliable caller (a "node") can cut off the flow of information to an entire branch of the tree.

- If you are relying heavily on your phone tree, send a test message asking the people at the end (the "fruit") to notify the tree organizer that they were called.

- Phone trees need a way to deal with nodes that don't get their assignment in a timely way. A good way to handle this is to have each caller report to the root before starting their calls. Nodes that don't report in by a certain time can be bypassed, with someone else being "assigned" their list.

- Have very clear policies about the purpose of the tree and when and by whom it will be triggered. Don't let it be used too often or triggered by one person in a panic.

- Make sure one or more people are responsible for maintaining the phone tree. It's a lot of work, but if it isn't pruned it won't be much good.

- Ask for confirmation that calls have been made.
Postal Mailings

Effective communication can also be achieved through the postal system. If you have the time, you can mail fact sheets and other informational material to the people and groups on your group's volunteer or supporter lists. Other organizations may also provide you with their lists.

Mailing can be expensive, and some organizations may be hesitant to share their lists. Sometimes your mailing can ride for free in other groups' mailings or newsletters if it doesn't significantly increase their postage, or if you help them fold and stuff. It's helpful to make a list of sympathetic newsletters and their mailing dates.
E-Mailings

Communicating by email is inexpensive and involves a rapidly increasing number of people. Include a request to forward the information to other interested people--this can spread your message well beyond your list. For sizable mailings, be sure to use the blind carbon copy (BCC) feature (most mailers have this), so that the entire distribution (the list of recipients' addresses) is not made available to everyone on the distribution. With BCC, each recipient will be copied on an email sent to you--and they won't see any other recipients.
Using Action Alerts

An action alert is a message that someone sends out via mail, fax or email asking for a specific action to be taken on a current advocacy issue.

Well-designed action alerts are a powerful way to invite people to participate in the democratic process. Here are some guidelines that are helpful for mail, fax, and Internet based Action Alerts:

- **Specify and summarize exactly what action you are calling for.** All too often action alerts fail to summarize EXACTLY what they wish the reader to do! At the end of your alert, and in as few words as possible, summarize the action you wish the reader to take. For Example:

  - *Action Needed:* Write a note, call, or E-mail a quick message to your legislator urging him/her to support the Traumatic or Acquired Brain Injury Act (S. 702, H.B.1271). People with disabilities as a result of brain injury desperately need minimum services and supports.

- **Establish authenticity.** Bogus action alerts -- such as the notorious "modem tax" alert -- travel just as fast as real ones. Don't give alerts a bad name. Include clear information about the sponsoring organization and provide the reader with several ways of tracing back to you -- e-mail address, postal address, URL or phone number. Including this contact information makes sense anyway -- you want people to join your movement and this means establishing contact with you. There's no substitute for clearly explaining who you are and giving people a way to reach you.

- **Put a date on it.** Paper mail and faxes get thrown away quickly, but action alerts can travel through the Internet forever. Even if an alert seems to have faded away, it can sleep in someone's mailbox for months or years and then suddenly get a new life as the mailbox's owner forwards it to a new set of lists. Do not count on the message header to convey the date or anything else; people who forward Internet messages frequently strip off the header. Give your recommended action a clearly stated time-out date, for example, "Take this action until February 17, 1998". If you think there will be follow-up actions, or if you want to convey that this is part of an ongoing campaign, say so. That way, people will contact you or look out for your next alert.
• Include clear beginning and ending markers. You can't prevent people from modifying your alert as they pass it along. Fortunately, this happens accidentally, as extra commentary accumulates at the top and bottom of the message as it gets forwarded. Put a bold row of dashes or something similar at the top and bottom so it is clear that extra comments have been added that way it will be very clear what you and your credibility are standing behind.

• Beware of second-hand alerts. Although it is uncommon for someone to modify the text of your alert, sometimes people will foolishly send out their own paraphrase of an alert, perhaps based on something they heard verbally. These second-hand alerts usually contain exaggerations and other factual inaccuracies, and as a result they can easily be used to discredit your alert. If you become aware of inaccurate versions of your alert, you should immediately notify relevant mailing lists of the existence of these second-hand alerts. Explain clearly what the facts are and aren't, implore the community not to spread the misleading variants, and provide pointers to accurate information including a copy of your own alert. This action has two virtues: first, it may help to suppress the mistaken reports; and second, it positions you as a responsible person who cares about the truth.

• Think about whether you want the alert to propagate at all. If your alerts concern highly sensitive matters, then you will probably want to know precisely who is getting your notices, how, and in what context. If so, include a prominent notice forbidding the alert's recipients from forwarding it.

• Make alerts self-contained. Don't presuppose that your readers will have any context beyond what they'll get on the news. People who have never heard of you or your cause will probably read your alert. So define your terms, avoid references to previous messages on your mailing list, and provide lots of background or at least some simple instructions for getting useful background materials. In fact, you might consider making the e-mailed alert relatively short and include the URL for a Web page that provides the full details. Your most important audience consists of people who are sympathetic to your cause and want to learn more about it before they can take action. Write your alert with that type of reader in mind, not the complete insider or the apathetic stranger.

• Ask your reader to take a simple, clearly defined, rationally chosen action. For example, you might ask people to call their representatives and express a certain view on an issue. In this case, you should provide the representative's name and number, and explain how to conduct the conversation: what to say, how to answer certain likely questions, and so on. For example, “Please phone Senator Brown and ask that he vote for the motorcycle helmet bill introduced by Senator Lynch.”
The purpose of such a script is not to impose your thinking but to help people to learn a skill that might otherwise be intimidating. Decide whether to ask for e-mail messages (which can be huge in number but near-zero in effect), written letters (which will be fewer but more effective), or phone calls (which fall in between).

- **Make alerts easy to understand.** It is crucial to begin with a good, clear headline that summarizes the issue and the recommended action. Use plain language, not jargon. Check your spelling. Use short sentences and simple grammar. Choose words that will be understood worldwide, not just in your own country or culture. Solicit comments on a draft before sending it out.

- **Get your facts straight!** Your message may well circle the earth, so double-check. Errors can be disastrous. Even a small mistake can make it easy for your opponents to dismiss your alerts -- and Internet alerts in general -- as "rumors." Once you do discover a mistake, it will be impossible to ensure that the correction reaches the same audience, but issue one anyway.

- **Start a movement, not a panic.** Do not say "forward this to everyone you know". Do not overstate. Do not plead. Do not say "Please Act NOW!!!" Do not rant about the urgency of telling everyone in the universe about your issue. You're not trying to address everyone; you're trying to address a targeted group of people who are inclined to care about the issue. If the issue really is time-critical then just explain why, in sober language. Do not get overly concerned with the immediate situation at hand. Your message may help avoid some short-term calamity, but it should also contribute to a much longer-term process of building a social movement. Maintaining a sense of that larger context will help you and your readers from becoming dispirited in the event that you lose the immediate battle.

- **Tell the whole story.** Most people have never heard of your issue, and they need facts to evaluate it. Facts, facts, facts. For example, if you believe that someone with a brain injury has been unjustly convicted of a crime, don't just give one or two facts to support that view. Most people will simply assume they are getting half the truth. If your opponents have circulated their own arguments, you'll need to rebut them. If they have framed the facts in a misleading way then you'll need to explain what's misleading and why. On the other hand, you need to write concisely. Even if you are focused on the actions, good explanations count more. After all, one of the benefits of your action alert -- maybe the principal benefit -- is that it informs people about the issue. Even if they don't act today, your readers will be more aware of the issue in the future, provided that you don't insult their intelligence today.

- **Don't just preach to the converted.** When you are very caught up in your cause, it is easy to send out a message in the language you use when discussing the issue with your fellow campaigners. Often this language is shorthand that doesn't really explain anything to an outsider. If you really care about your issue, you'll take the time to find language that is suitable for a much broader audience. This can take practice.
Avoid righteous language. Your readers should not have to feel they are being heckled to go along with something from the pure fairness of it. You will not succeed unless you assume that your readers are reasonable people who are willing to act if they are provided with good reasons.

Make it easy to read. Use a simple, clear layout with lots of white space. Break up long paragraphs. Use bullets and section headings to avoid visual monotony. If your organization plans to send out action alerts regularly, use a distinctive design so that everyone can recognize your "brand name" instantly.

Do not use a chain-letter petition. A chain-letter petition is an email / Internet action alert that includes a list of names at the end; it invites people to add their own name to the list, send in the petition if their name is the 30th or 60th etc, and forward the resulting alert-plus-signature-list to everyone they know. This idea sounds great in the abstract, but it really doesn't work. The problem is that most of the signatures will never reach their destination, since the chain will fizzle out before reaching the next multiple of 30 in length. What's even worse, a small proportion of the signatures will be received in the legislator's office many times, thus annoying the staff and persuading them that they're dealing with an incompetent movement that can never hold them accountable.

Urge people to inform you of their actions. Include an email address of phone number for people to report back on the action they have taken. If you are calling on people to telephone a legislator's office, for example, you should provide an e-mail address and invite them to send you a brief message. Explain that you'll use these messages to count the number of callers your alert has generated, and that this information will be invaluable when you speak with the legislator's staffers later on.

Don't overdo it - avoid action alert fatigue! Action alerts might become as unwelcome as direct-mail advertising. Postpone that day by picking your fights and including some useful, thought-provoking information in your alert message. If you're running a sustained campaign, set up your own list. Then send out a single message that calls for some action and include an advertisement for your new list. If you must send out multiple alerts on the same issue, make sure each one is easily distinguishable from the others and provides fresh, useful information.

Do a de-brief. When the campaign is over, try to derive some lessons for others to use. Even if you're burned out, take a minute right away while the experience is still fresh in mind. What problems did you have? What mistakes did you make? What unexpected connections did you make? Who did you reach and why? Which groups or mailing lists were your alerts forwarded to? Which of these forwarding actually caused people to take action? Good guesses are useful too.
• **Don't mistake mail, faxing and e-mail for organizing.** An action alert is not an organization. If you want to build a lasting political movement, at some point you'll have to gather people together. Action alerts are useful tools for organizing, but it's just one tool and one medium among many that you will need. You should evaluate alerts in terms of its contribution to larger organizing goals. Do the people you reach through alerts move up into more active positions in your movement? Do you draw them into conferences, talk to them by phone, meet them in person, and become accountable to them to provide specific information and answer questions? If not, why do you keep reaching out to them?
Samples
Greetings, Everyone -- When the kids are back at school and Congress returns the first part of September, they (Congress, not the kids) will have only 17 working days left to complete business before their tentatively-scheduled adjournment date of October 6. There are many issues that still need our attention, not the least of which is the still-pending TBI Act. We realize that we are handing you a lot of information on a number of important issues and that you won't be able to address all of them. That's fine. Please, just pick the one or two (in addition to the TBI Act) that interest you most -- and let us hear of your efforts and the response you get.

TBI Act

Focus on P & As and National Toll free Line -- The TBI Act amendments remain part of the Children's Public Health Act of 2000, S. 2868. Congressional staff continue to work on parts of the bill during the recess, and it's an excellent time for constituents to continue to visit members of Congress. We still expect that the bill may receive a "mark-up" in the Senate Health, Education, Labor and Pensions Committee in September. (If not, the bill will have to be re-introduced next year in the 107th Congress.)

ACTION -- Visit, call, write or fax your Senators asking them to support the TBI Act provisions of S. 2868, including the all-important items listed above. Members of the Senate Health, Education, Labor and Pensions Committee are still priority (see list at the end of this Policy Corner), but even if your Senators are not on the Committee, they can help by contacting committee members and urging their support for the TBI provisions. And if the bill happens to go straight to the floor, every Senator's vote is of equal importance.

Talking points

- Protection and Advocacy (P & A) Services -- Of utmost importance to people with brain injury and families is access to services and programs. Whether education, employment or housing, it's no secret that this access does not exist on a broad and evenhanded basis. Protection and Advocacy (P & A) services exist in every state to assist people with a variety of disabilities to access services and supports. All we are asking is that Congress give the P & A systems the authority specifically to serve people with TBI.
Status: This provision is not in the bill introduced in the Senate; nor was it in the bill passed by the House. There is a significant amount of support, however, in both Houses. We feel that if we can just get it into the bill that finally passes the Senate, there is a good chance the House will concur in conference.

- **Toll-Free Information Line** -- We have long proposed a **Toll-Free Number** as part of CDC's responsibilities. The toll-free number would benefit people with brain injury, families and professionals and would raise awareness about TBI. Through one call to a national number, managed by the Centers for Disease Control and Prevention, callers would be linked immediately to resources in their own state or local area.

Status: While information from around the country indicates that such a centralized national number could be extremely helpful in linking people with the supports they need in a timely manner, our sponsors in the Senate and the House have, thus far, decided to "leave it up to the states".

**PLEASE, make those calls, and write those letters. Your delegation needs to know where you stand, and the future of the TBI Act depends on it.**

---

**Health**

**Family Opportunity Act** -- The Family Opportunity Act of 2000 (FOA), S.2274 now has 70 co-sponsors in the Senate - 40 Democrats and 30 Republicans. The House bill has 65 bi-partisan co-sponsors. The FOA is a pragmatic and responsible policy effort that will help ensure that fewer children are uninsured and more children with disabilities have access to a broad range of needed health care services and supports. The most critical provisions of the bill would allow states (state option) to offer Medicaid coverage, on a sliding scale "buy-in" basis, to middle-income families to cover their children with severe physical or mental disabilities. These children are often ineligible for Medicaid because their families make too much money. They may be uninsured or underinsured because health insurance is not available through an employer, is too expensive or offers a very limited benefits package. The bill also includes an Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. A third section of the bill would set up family-to-family health information centers.

**ACTION**

- **Urge your Representatives to co-sponsor the FOA.** Also urge them to ask House Republican (Rep. Hastert, R-IL) and Democratic (Rep. Gephardt, D-MO) leaders for floor action as soon as possible.
- **Contact Chairman Bliley (R-VA).** Ask him for quick action in the House Commerce Committee.
- **Urge your Senators to co-sponsor the FOA and to ask Senate Republican (Sen. Lott, R-MS) and Democratic (Sen. Daschle, D-SD) leaders for floor action as soon as possible.**
Patients Bill of Rights/Managed Care Reform -- Consumers are one vote away from getting a real patients’ bill of rights. In June, the Senate passed yet another weak bill - a "patients' bill of rights" in name only - but it is going nowhere. When the Norwood/Dingell bill comes back to the floor of the Senate this fall, just one more vote is needed for it to pass. This is an issue that has survived several sessions of Congress. This is an election year. It is time to let your Members know that you expect them to support managed care legislation that meets the needs of children and adults with disabilities and their families.

ACTION

• Meet with Members in their district office and attend their public events. Ask questions about his/her support of the Norwood/Dingell bill. Encourage Members to oppose bills, like the latest proposal from Sen. Nickles (R-OK) that was particularly bad for people with disabilities.

• Thank the Senators and Representatives who have remained steadfast in their support of real reform, especially the 19 House Republicans and the four Republican Senators -- Chafee (RI), Specter (PA), Fitzgerald (IL) and McCain (AZ) -- who have supported stronger reforms.

Long-Term Care and Retirement Security Act -- In March, Sens. Grassley (R-IA) and Graham (D-FL) and Reps. Johnson (R-CT) and Thurman (D-FL) introduced S.2225 and H.R. 3872, the Long-Term Care and Retirement Security Act of 2000. These bills would make it easier for people with disabilities who live in the community, or their families, to pay for long-term supports and services. The bills would amend the tax law to give a $3,000 tax credit for individuals with long term care needs, allow individuals a deduction for qualified long term care insurance premiums and allow them to use such insurance under cafeteria plans and flexible spending arrangements. There has been no action taken yet on this proposal.

ACTION -- Urge your Senators and Representative to co-sponsor the Long-Term Care and Retirement Security Act making it easier for people with disabilities who live in the community to pay for long-term supports and services.

Waiver of Naturalization Oath for People with Certain Disabilities -- Sen. Hatch (R-UT) introduced a bipartisan bill (S. 2812) that would allow the Attorney General of the United States to waive the oath of allegiance for people with disabilities who seek naturalization but who cannot understand or communicate an understanding of the required oath of allegiance. The Senate Judiciary Committee voted favorably on the bill and it passed the Senate on July 21. The bill has been reported to the House and referred to the House Judiciary Committee. House action is needed in September if the bill is to be signed into law this year.

ACTION -- Urge your Representatives to co-sponsor and support passage of a House version of S. 2812. Personal stories have been especially effective on this bill. If you know of families who have been unable to naturalize a member with a disability because he/she is deemed unable to understand the oath of allegiance, try to get the family to make personal contact with the Representative.
**ADA Protections** -- Rep. Foley (R-FL) introduced a bill in February (H.R. 3590) that would weaken the ADA. *H.R. 3590*, the **ADA Notification Act**, would create a new requirement for 90-days notice to a defendant before an advocate or attorney could initiate new litigation. There are currently 14 co-sponsors. The House Constitution Subcommittee of the Judiciary Committee held a hearing on the bill on May 18. Three panels presented testimony, including one composed of the bill's main co-sponsors, Reps. Foley and Shaw (R-FL) and actor Clint Eastwood. Subcommittee Chair Canady (R-FL) did not appear completely supportive of the bill. Rep. Foley, however, threatened to try to pass H.R. 3590 under suspension of the rules the week of July 17. Fortunately, there was not enough support to pass the bill in this manner. Sponsors may now take a different strategy and try to attach the bill as a Rider (amendment) to another bill, such as the appropriations bill.

**ACTION** -- Urge your Members of Congress to reject *any* weakening amendments to the ADA.

**Events**

**Rolling Freedom Express and March for Justice -- "Don't Tread on the ADA"**

The Americans with Disabilities Act (ADA) is under attack. In early October, the Supreme Court will hear the Garrett case and the constitutionality of the ADA will be decided.

The "Rolling Freedom Express" is a bus tour that will start in Alabama (the state that challenged the constitutionality of the ADA), pass through 7 states and end up in Washington, DC, September 30th. At each stop along the "Rolling Freedom Express" an event is being organized. A list of stops is at the end of this **Policy Corner**.

Supporters are encouraged to join the Express along the way or organize a local caravan to get people to the "Rally and March for Justice" -- at noon, Tuesday, October 3, in Washington, DC, Upper Senate Park, near the Supreme Court, where thousands of ADA supporters will gather to send the message.

**ACTION**

- Organize a local caravan to get people to the Rally and March.
- Organize a local event on October 3rd to call attention to this threat to our civil rights and the national Rally and March.
- Participate in the event nearest you.
- Get your local public officials to sign the Spirit of ADA Pledge, [http://www.spiritofada.org](http://www.spiritofada.org), under Pledges/Petitions.
- Purchase "ADA: Rights Worth Fighting For" bumper stickers, minimum order 100 -- see below for where to order.
- Make a financial contribution to support the Express, Rally and March.
- Distribute this invitation.
For more information on the 'Rolling Freedom Express" contact Jim Ward at NAPAS, 202-408-9514 or call 512-442-0252. For information on the ADAPT week in DC, Sept. 30th - Oct. 5th call 303-733-9324

LOCAL COORDINATORS: Date/City/Contact
Fri. Sept. 22nd, Birmingham, AL, TBA
Sat. Sept. 23rd, Atlanta, GA, Mark Johnson, 404/350-7490
Sun. Sept. 24th, Nashville, TN, Paul Ford/Tim Wheat, 615/269-8530 or 901/726-6404
Mon. Sept. 25th, Louisville, KY, Sue Davis, 502/585-4426
Tues. Sept. 26th, Columbus, OH, Woody Osburn, 614/463-1444
Wed. Sept. 27th, Pittsburgh, PA, Jim Glozier/John Lawrence, 724/223-5115
Thurs. Sept. 28th, Harrisburg, PA, Linda Anthony, 717/238-0172
Fri. Sept. 29th, Philadelphia, PA, Erik Von Schmetterling/Jimmi Schrod/Nancy Salandra, 215/627-7255
Sat. Sept. 30th, Baltimore, MD, Crosby King, 410/666-5484
Sat. Sept. 30th, Washington, DC, Bobby Coward, 202/397-1668

Quote for the Week:
"Opportunity is missed by most people, because it is dressed in overalls and looks like work."

Thomas Edison

Brain Injury Association, Inc.
105 North Alfred Street, Alexandria, VA 22314
Ph. 703-236-6000, Fax: 703-236-6001
www.biausa.org

Janna Starr Director of Public Policy
6022 Sunnyview Rd. NE, Salem, OR 97301
Ph. 503-375-6373, Fax: 503-375-6439
JannaStarr@att.net

20 years of creating a better future for people with brain injury and their families

Sample Action Alert

So You Wanna Be An Advocate...? • Brain Injury Association of America • 2001 • www.biausa.org • (703) 761-0750
Greetings, Everyone -- This just in -- The Social Security Administration (SSA) last week published a Notice of Proposed Rule Making (NPRM) in the Federal Register. This proposed rule would, among other things, automatically adjust each year the Substantial Gainful Activity level for individuals with disabilities other than blindness. These adjustments would be based on increases in the national average wage index. This is a proposal, NOT a final rule. We, therefore, need to write SSA supporting this and the other very positive proposed changes listed below and commenting on how they will benefit people with disabilities from brain injury or other causes who want to work.

SSA is also proposing in this NPRM to:

(1) Provide that they will ordinarily find that an employee whose average monthly earnings are not greater than the "primary substantial activity amount" (currently $700) has not engaged in substantial gainful activity without considering other information beyond the employee's earnings. (In other words, they are proposing eliminating the "secondary" SGA level.)

(2) Increase (from the current $200 to $530) the minimum amount of monthly earnings that they consider to indicate that a person receiving SSDI is performing or has performed "services" during a trial work period.

(3) Increase the maximum monthly (from $400 to $1,290) and yearly (from $1,620 to $5,200) Student Earned Income Exclusion amounts we use in determining SSI eligibility and payments. They also will automatically adjust the monthly and yearly exclusion amounts each year thereafter based on any increases in the cost-of-living index.

ACTION -- In order for SSA to consider public comments on these specific proposals, they must receive them by October 10, 2000.

Comments should be submitted in writing to the Commissioner of Social Security, P.O. Box 17703, Baltimore, MD 21235-7703; sent by fax to (410) 966-2830; sent by E-mail to "regulations@ssa.gov"; or delivered to the Office of Process and Innovation Management, Social Security Administration, L2109 West Low Rise, 6401 Security Boulevard, Baltimore, MD.
For more information, go to http://frwebgate.access.gpo.gov, or to the SSA web site http://www.ssa.gov.

Brain Injury Association, Inc.
105 North Alfred Street, Alexandria, VA 22314
Ph. 703-236-6000, Fax: 703-236-6001
www.biausa.org

Janna Starr Director of Public Policy
6022 Sunnyview Rd. NE, Salem, OR 97301
Ph. 503-375-6373, Fax: 503-375-6439
JannaStarr@att.net

20 years of creating a better future for people with brain injury and their families
Sample:

Brain Injury Association of America

Phone Tree

When a message is passed to you, please call the people in the boxes immediately below your name. If you cannot reach a live human being, please leave a message, but call the people on the next rung down, too. If the information listed for you is incorrect or incomplete, please contact Judy at 800-523-5438

<table>
<thead>
<tr>
<th>BIA-WA Phone Tree</th>
<th>Rich Wilson 800-523-5438 w § <a href="mailto:rcwils@yahoo.com">rcwils@yahoo.com</a></th>
<th>BIA-WA Phone Tree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wally Walsh 555-555-1212 h § <a href="mailto:wwalsh@seanet.com">wwalsh@seanet.com</a></td>
<td>Ed Miller (425) 895-0047 w § <a href="mailto:biawa@biawa.org">biawa@biawa.org</a></td>
<td></td>
</tr>
<tr>
<td>Rachel O’Connor 505-474-3583 w § <a href="mailto:roconnor@biausa.org">roconnor@biausa.org</a></td>
<td>Geoffrey Lauer 319.384.9299 w § <a href="mailto:glauer@biausa.org">glauer@biausa.org</a></td>
<td></td>
</tr>
<tr>
<td>Janna Starr 503-375-6373 w § <a href="mailto:jstarr@biausa.org">jstarr@biausa.org</a></td>
<td>Lou Nash 425-776-7264 h §</td>
<td></td>
</tr>
<tr>
<td>Jim Black 555-5555</td>
<td>John Brown 555-1111</td>
<td>Sam White 555-8888</td>
</tr>
<tr>
<td>Mary Smith 444-1111</td>
<td>Jane Baker 444-7777</td>
<td>Edna Miller 444-9999</td>
</tr>
<tr>
<td>Frieda Mason 444-6666</td>
<td>Maria Lopez 333-1111</td>
<td>Mason Friel 333-2222</td>
</tr>
<tr>
<td>Simon Fraser 333-4444</td>
<td>Tim Zora 333-8888</td>
<td>Zane Grey 999-8888</td>
</tr>
<tr>
<td>Sally Caller 999-7777</td>
<td>Fred Boast 999-4444</td>
<td>Sara Monro 999-2222</td>
</tr>
<tr>
<td>Tonga Xanda 666-8888</td>
<td>Agnes Minor 666-7777</td>
<td>Juan Mural 666-7788</td>
</tr>
<tr>
<td>John Rock 777-9988</td>
<td>Shawn Truan 887-8899</td>
<td>Shelly Compatico 887-8899</td>
</tr>
<tr>
<td>Bill Super 559-9977</td>
<td>Ten Penh 445-5544</td>
<td></td>
</tr>
</tbody>
</table>
Exercises

**Exercise One:** Imagine that you are spearheading a major piece of legislation to increase services for persons with brain injuries in your state. You want to build a coalition of interested parties. List some organizations in your state that will be interested in participating:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

**Exercise Two:** What informational material will you give people who are interested? Fact sheets, sample letters, petitions?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

**Exercise Three:** Develop the “roots” of a phone tree for your advocacy efforts. What individuals or organizations can you count on to be the first contacts? What volunteers?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
Using the Media Effectively
Learning Goals

1. Participants will be able to identify when and how to use the media to effectively promote their issues.

2. Participants will learn how to engage the media by effective outreach and the writing of public service announcements and press releases.

3. Participants will learn important steps in writing letters to the editor and opinion editorials.
Effective Use Of The Media
In Advocacy Efforts

“Airing the plethora of viewpoints on a topic is essential to informed, thoughtful
decision making. An informed citizen is the bedrock of our democracy and the
guardian of our rights.” -Peter Kent, editorial page editor, Atlanta Journal

Using the media is a tremendously effective way to promote your organization’s activities and
further advocacy efforts. Becoming familiar and friendly with local reporters is essential, since
they will be the ones writing stories about your organization. Reporters of interest to your
organization typically will be medical/health reporters, local and lifestyle editors for newspapers,
as well as news assignment editors and public service directors for radio and television. Develop
a thorough media list and keep it updated.

Reporters are looking for fresh and timely newsworthy stories; however, many news releases or
potential events do not receive media coverage because they lack a local angle, were poorly
written or were sent to the wrong person. Listed below are some ways to use the media to
disseminate your message:
Writing Effective Letters To The Editor

Letters to the editor are an easy way for you to voice your opinion to your policymakers, and to educate people in your community about the issues. You can use letters to correct or interpret facts in response to an inaccurate or biased article that was published to explain the connection between a news item and your priority issues, or to praise or criticize a recent article or editorial. Whatever your purpose, your letter will reach many people in your community. Without exception, the letters section is one of the most highly read segments of newspapers and magazines.

The following tips will help you fine tune your letter writing skills, and will increase your chances of getting published.

Steps To Success:

- **Know Your Paper's Policy:** Find out the publications policy for printing letters. Some have requirements for length of letters, some want letters to be type written, and almost all require that you include your name, address and phone number. Of course your address and phone number would never be printed - most publications will want to call you before they print your letter to confirm that you really did write the letter and that you want to have it published.

  If the paper doesn't publish their letter requirements next to the letters it prints, don't be afraid to call. Ask to whom you should address your letter, if they have any length restrictions, and in what format is preferred.

- **Be Timely:** Responding to a recent article, editorial or op-ed is one of the best ways to increase your chances of getting published. Be sure to mention the name of the article and the date it was written in the beginning of your letter. You can also capitalize on recent news, events, or anniversaries. For example, Brain Injury Associations can use Brain Injury Awareness month to write about issues of importance to the brain injury community.
• **Keep it Simple:** Your letter should be concise, informative and personal. Keep your points short and clear, stick to one subject, and as a general rule, try to keep your letters to less than three to four paragraphs in length. Make your first sentence short, compelling and catchy. Don't be afraid to be direct, engaging, and even controversial.

• **Get Personal:** Newspapers, at their core, are community entities. Editors will be much more likely to publish a letter, and the letter will have much more impact if it demonstrates local relevance.

• **Use local statistics.** For example, use statistics about people with brain injury in your state.

• **Use personal stories.** For example, if you or someone in your family has recently been injured and is having difficulty obtaining appropriate services, tell that story.

• **Use names.** As legislative aides have repeatedly told us, if a letter to the editor mentions a Representative or Senator's name, they will see it. They care about how they are being perceived in the district, and they will pay attention to a letter which asks them to co-sponsor legislation or to take a specific action. You should also urge your readers to support your position and to let their elected officials know their views.

• **Use your credentials.** If you have expertise in the area you are writing about, say it!

• **Don't Forget the Follow-up:** Don't be discouraged if your letter is not printed. Keep trying. You can even submit a revised letter with a different angle on the issue at a later date. If your letter is published be sure to send it to your member of Congress and to the Brain Injury Association national office! While your Representative or Senator will probably have clipped your letter, it carries more weight if it comes from you with a personal note attached.

• **Think Strategically:** You should think about letters to the editor as a regular strategic campaign tool to increase the effectiveness of your advocacy efforts. Try to target several different papers in your district at the same time and encourage people to explore different angles on the same issue.
Writing And Publishing An Op-Ed

Op-eds, opinion/editorials, are articles that appear opposite the editorial page of local, state and national newspapers. They are written by local citizens, experts, leaders of organizations -- people like you. And they are an extremely powerful and cost-effective way to both educate a large number of people about our issues, and to influence policymakers.

Steps To Success:

**Timing is Everything:** Timing is the most important factor in deciding to submit an op-ed. Is the state legislature about to cast a controversial vote that impacts people with brain injury? Can you tie the op-ed to the release of a new report, a recent article, a popular movie, or an event in your community?

The Elements of Style:

- **Writing, editing and distributing an op-ed is easier than you think.** Keep your text to between 500 and 800 words (about 3 pages double-spaced). Stay focused on one issue. Think creatively and try to be original. (Tip: read op-eds before starting so you see how they are styled.)

- **Highlight the issue's relevance.** Begin with a short story illustrating how the issue affects an individual or group of people to drive home why the newspaper's readers "need to know."

- **Use local statistics.** For example, in an op-ed focusing on persons with brain injuries, be sure and include statewide statistics on brain injury.

- **Op-eds should, by their "biased" approach, provoke discussion, controversy and response.** If you are trying to get your member of congress to co-sponsor a particular piece of legislation, say so. Mentioning the member's name guarantees s/he sees it. In addition, op-eds should be informative and provide practical solutions for the problem you have presented.

- **It's the Messenger and the Message.** Finding the best author, or signer, of the op-ed is also critical in achieving the publication of the article in addition to maximizing its impact. Within your core groups you have numerous people with different expertise and experience. Choose from among yourselves, or ask a local doctor, business executive, local elected official to sign the op-ed -- anyone who may be perceived as having an interesting perspective on the issues.
The Basic Questions:

- **How do I format an op-ed?**
  Double space your text. Provide a suggested title, the author's name and identification. You may want to include a short biographical paragraph about the author, including residence and experience relevant to the topic. You can include a short cover letter, highlighting the most important aspects of the op-ed, but it is not required.

- **When should I send the op-ed?**
  You will need to allow some time for the media to review and edit the piece, usually about one to two weeks. You will also want to make sure that the ideas in the op-ed have time to impact policymakers once the piece is published - just enough time for you to clip the article and send it with a letter to your local Brain Injury Association, your Regional Director, your national Association, the provider community and any elected officials in your area.

- **Where do I send my op-ed?**
  Identify the largest newspaper in your state or area for maximum exposure. Call the paper first to ask for the name of the op-ed page editor. If it is a local paper with a circulation of less than 40,000, you may have to send it to the editorial page editor, or the chief editor. Get the correct spelling and address and send it off.

- **How should I follow-up?**
  After 3-10 days, you should call the editor and ask if your op-ed is under consideration. Think of your follow-up call as an opportunity to educate the editor about the issue - even if your op-ed is not published. If your rapport is good, suggest a meeting, or ask if there is a reporter who should get a copy as background on the issue. The result could be a relationship with the editor, which will prove helpful for the future.

- **What can I do with the op-ed after it is published?**
  Make sure to clip your published op-ed, make a copy of it, including the name of the paper and the date it was published, and send it to the policymaker you want to influence as soon as possible. Keep copies to use for your advocacy efforts, and be sure to send a copy to the Brain Injury Association of Missouri and the national Brain Injury Association.
Radio Public Service Announcement (PSA)

As a result of its national, local and community presence, radio is a very effective medium to convey educational messages, such as public service announcements. Virtually every community has a local radio station, most of which readily will give free air time to nonprofit organizations which have prepared public service announcements (PSAs). Individuals from all age groups listen to the radio, which makes it easy to tailor your messages to a specific demographic.

Below are some tips to follow when composing your PSA’ and submitting them to radio stations.

**Before submitting a PSA, contact radio stations about their policies on accepting PSAs:**

- How far in advance should the PSA be submitted? Ask for a deadline.
- How long should the PSA be?
- Identify a point of contact at the station to whom your PSAs should be sent (usually the public service director).
- Ask if radio personalities will read the PSAs on air themselves or whether you need to have them taped in advance by someone else.

**When writing PSA’s, keep the following in mind:**

*Keep it simple.* Sentences must be short and to the point. People remember messages that are simple and make succinct points.

*Avoid editorializing.* Radio stations want to deliver factual information, not someone’s personal point of view.

*Do not ask for money.* PSAs either should deliver a clear, factual message or be a call to action for volunteers.
All PSAs must answer the “5 W’s”. Who, what, when, where and why. The PSA also must be printed on your organization’s letterhead.

- Use a local angle in your PSA. Localizing your message will help people relate. Remember, you are competing for attention, and if your message “hits home,” it more likely will be remembered.

- Time your message – typically, radio PSAs are 15, 30 or 60 seconds in length.

- Develop a timeline. Most radio stations want written PSAs three to four weeks prior to when you want them aired.
Radio/Television Appearances

One idea is to have an expert discuss a particular topic as a guest on a talk show. Talk with the producers and editors of the show you have targeted. Be prepared to discuss possible story angles and offer potential guests and/or experts. As with all of the media, you must “sell” your story to them by hooking their interest. Remember that radio disc jockeys usually enjoy on-air “chat” in between songs or during special “public service” programs (many air early on Sunday mornings) and always are looking for newsworthy information to share with their listeners.

Before “pitching” story ideas to a radio or television program, check to see whether they have a preferred timeframe in planning non-news stories. For example, some television shows have program ideas planned three or four weeks in advance. If your program idea focuses on a time-specific topic (e.g., Brain Injury Awareness Month; bicycling safety), make sure it is pitched at the appropriate time.

Information on a program’s planning schedule is included in the *Bacon’s Television Media Directory*, which usually can be found at most libraries.
News Conferences

This option only should be considered if you have a newsworthy announcement, such as new research or a celebrity endorsement. News conferences are most effective if you schedule them mid-week (Tuesday through Thursday). It is important to verify that the facility where you plan to hold your event can accommodate your space, equipment and other needs. News conferences should be kept to less than 40 minutes and should use no more than three speakers.

It is important to distribute media alerts and to call the day before the event to gauge attendance. Keep in mind that print and television reporters prefer visual images to accompany the story. Make sure that you display your organization’s name and logo prominently. Distribute press kits that include a press release, information about your organization, biographies of the featured speakers and other background material which the media might find useful when covering the story. Remember, the easier you make a reporter’s job, the better the coverage of your story will be and the more likely reporters will want to work with you on other projects! It also is nice to set up a “welcome table” for the media where they can register and perhaps find light refreshment.
Media Advisories (Media Alerts)

The purpose of a media advisory (also referred to as a media alert) is to get members of the press to attend and cover an event that you are promoting. A newsworthy event may be a press conference, fundraising event or program to give away bicycle helmets at a local school. The advisory will provide the press with the who, what, where, when and why.

Note: You should produce both a media advisory and a press release for a specific event. The media advisory is intended to get the press to attend and cover the event; a press release is intended to provide the actual story or pitch enough of the story to get a reporter to do a follow-up story based on your press release.

A media advisory should:

- Have contact information, including media point of contact name, phone number, fax and e-mail.

- Type the words "MEDIA ADVISORY" centered on the page below the contact information.

- Describe in a very clear format the "who," "what," "when," "where," and "why" of the event.

- Suggest potential story opportunities or photo opportunities

- Be generally no more than one page.

- End with "###".

Follow up personally if you can, asking if the advisory was received, if the event was assigned, and if more information is needed.
Press Releases

Press releases are stories you write to alert the media and to entice them to do a story. It is written just like a news story so a reporter or editor can envision having something worthy to report, and to help a reporter in putting a story together. Knowing the basics of news writing helps a lot. When writing a press release:

- At the very top, write "PRESS RELEASE."
- At the top left, include "For immediate release" and the date of the press release. If you want the media to stay quiet until some later time, use "For release on date and time." This may shift the focus from "cover us, please" to "you can have this sensitive and important information."
- At the top left, include the name of your organization and its contact information. Make sure there is enough contact information for a reporter to reach someone whenever they happen to try, day or night.
- When sending your press release to publications, be sure it is addressed to a specific person rather than sent “blindly.” You can find out which individual at specific publications should receive your press releases by looking in the Bacon's Newspaper Media Directory, which usually can be found at most libraries.
- Create an appropriate and interest-generating headline. Be sure and use verbs in your headline.
- Start the story text with a "lead" that hooks a reporter or editor, just like a news story is supposed to hook a reader or listener.
- The body of the release should elaborate the story, the most important information coming first. Include quotes and attribute information to their sources.
- Put "###" at the end of your release.
• Including a photograph (active, not posed) helps. Glossy paper, well-focused, 8"x10"s are best. Provide information, including a caption and the name of the photographer, on an attached page (not on the back of the print).

• Type your release, on letterhead if possible, double spaced and one-sided.

• For multiple page releases, use "(more)" at the bottom of each continued page. Use a one-word "slug" (or descriptor suggestive of your headline) and a page number at the top of each continuation page. For example: UNFAIR -- page 2.

Follow up personally on your release if you can, asking if it was received, if a story will be done or if more information is needed.
Press Kits

Press kits are packets of additional information that are included with press releases or media advisories. This includes: fact sheets, a page of quotes by authoritative sources, past press releases, press clippings, and anything else a reporter could use. Press kits make it more likely a reporter or editor will believe there is enough substance to do a story.
List activities, meetings, seminars and special events in the calendar section of your local newspapers and/or newsletters. Once you identify your target audience, you will be able to select the appropriate publications for these notices (e.g., church newsletters, hospital newsletters or bulletin boards, library bulletin boards, school newsletters, and others).
Consider the many sources for placement such as the Internet. Use of the Internet increases dramatically every day. If your organization has a web site, it is essential that you place as much information as possible about your events on it. Because textual space virtually is unlimited on the Web, reporters and other interested parties can retrieve all the information they may need on your activity by researching your web site. Provide them links to other resources and let them know how they can get in touch with a “live voice” at your organization.

You can also utilize the Internet as a resource for information you need. In addition to obtaining facts on brain injury from the Center For Disease Control’s site at www.cdc.org, there are also many sites that provide contact information on print and broadcast media in your state.

The following web sites are helpful in your efforts to know how to contact the media:

- **www.n-net.com** - The Newspaper Network. This site allows you to search for newspapers listed by state.

- **http://ajr.newslinker.org** - A site hosted by the *American Journalism Review*. This site provides a listing of newspapers, magazines, television and radio stations across the country.

- **www.radio-directory.com** - BRS Media hosts this site, which allows you to locate and identify radio stations by state or call letters.
Samples
It’s day 100 of a journey of undetermined length and destination.

A hundred days ago on Halloween, my eldest son Bryan was savagely beaten in a downtown Albuquerque alley. His assailants, described by witnesses as a band of 14 “skinheads,” left him lying in a pool of blood with a sheared brain injury that placed him in a coma for 21 days. Against the odds, my son, who is 29 years of age, has regained consciousness, and now he is beginning to move toward an elusive goal known simply as recovery. My son is lucky; he has been surrounded and assisted by loving family members, friends and caregivers who have bonded together to assist him and one another in this journey that has been both sorrowful and spiritual. We are grateful.

Despite his “miraculous recovery” my son’s progress is measured one tiny step at a time. He started by gingerly squeezing my hand, and now has progressed to expressive language. He is walking with the aid of a walker, and has moved from soft foods to finely chopped foods as a regular diet. Yet his right side remains affected and his short-term memory is not yet intact. Bryan’s recovery has been termed by St. Joseph’s as miraculous. Fifty percent of patients who linger in prolonged states die within the first year; half of those who survive spend the rest of their lives in a nursing home. Some, like Bryan, have sensational recoveries and return to full functioning; others need long-term support to assist them and their families for life.

Bryan is not alone in New Mexico. According to the New Mexico Brain Injury Advisory Council, we have over 4,000 brain injuries each year, 1,200 of which are classified as “severe.” Known as the “walking wounded” these individuals appear normal but have sustained injuries to the brain that are visible only to the trained eye. In New Mexico they are victims of car accidents, assaults, falls or other seemingly random events. They are the survivors who are forgotten in the often traumatic circumstances of their personal tragedy, and they include such New Mexico residents Paul Cravens of the Gordon House incident and Ron Light of the Judith Neeley case. They also include former President Reagan’s press secretary James Brady, coma patient Karen Ann Quinlin, the great Muhammad Ali, racecar driver Stan Fox and others. Famous or forgotten, most are eventually abandoned by the traditional resources designed to care for them, including private insurance, Medicaid waivers, and other state and federally funded programs.

In New Mexico, the need is enormous, and the resources are scarce. Survivors, most of whom are young and male, fall between the cracks of the systems provided by the New Mexico Department of Health. The Developmental Disabilities system provides help only to those who are injured prior to the age of 21, excluding those individuals such as my son. The Disabled and Elderly Waiver system designed to serve adults caters to the elderly, and is poorly equipped to either admit or serve someone who needs progressive and intensive cognitive services geared to enhance independence. Even medical and care insurance is of little help for a long-term disability. Most persons with brain injuries liquidate their resources in the first year.
In New Mexico, almost all are without services and 82 percent are released home to their families for care. Over 30 percent of families of people with brain injuries have a family member who leaves a job to care for the injured person, thus making the impact both social and economic. Funds for services for people with brain injuries in the state of New Mexico now total $400,000, which would not be enough to cover my son’s medical costs let alone provide long term care for him and 1,200 other people each year.

Driving while intoxicated (DWI) and violent crime will always occur in New Mexico. While I applaud the prevention efforts of both, I appeal to both the Legislature and the governor to remember the victims when they are creating policy, allocating funds and pondering vetoes. I challenge them to walk one mile in my shoes and consider the following. It is unfair to spend $22 million dollars a year on DWI prevention when the victims are largely uncompensated, unassisted and unnoticed by our state systems. Services should not be available on a random basis, and funding should be made available through the Department of Health to assist those in dire need of help from being victimized, and who sustain traumatic, permanent disabilities. And while increased prison space may be necessary, it most certainly does not supersede a victim’s right to receive services for a crisis precipitated by social conditions. And lastly, the spending of a few dollars to alleviate stress is inconsequential compared to the many dollars we will be spending later to repair the damage of economic loss and overburdened families stretching to take care of loved ones at home.

My son Bryan is home now, and his improvement has been marked and steady. At day 100, we still do not know what the future brings.

Robert R. Patterson
Dear Editor,

Playing sports is a national pastime many people participate in, and for some, it even is a way of life. Throughout history people have played games as a recreational and stress-relieving activity. However, what people often fail to realize when playing sports is that—no matter how much talent they may possess—they still are human and injuries do occur.

Much to the chagrin of sports fans, there has been a recent rash of high-profile athletes sustaining numerous concussions. Perennial all-stars such as Steve Young of the San Francisco 49ers, Troy Aikman of the Dallas Cowboys and Eric Lindros of the Philadelphia Flyers have been making headlines lately, not for their on-the-field pursuits but for their off-the-field health problems in dealing with injuries caused by multiple concussions. These injuries unfortunately have reminded us how fragile the human brain really is.

The fragility of the brain and the lack of information and knowledge surrounding concussions and other brain injuries are the main reasons October has been designated Brain Injury Awareness Month. This public education initiative seeks to teach people about brain injury and its consequences, correcting misperceptions such as the idea that there is no such thing as a mild concussion or a mild brain injury. Concussions – defined as an alteration in mental status due to the brain shaking inside its protective skull -- are the most recognizable and frequent type of brain injury. For instance, football is responsible for approximately 100,000 concussions in the United States each year. Football players with brain injuries are six times as likely to sustain new injuries.

It would be in the best interest of everyone to take any precautionary measure possible to prevent these types of injuries from occurring. The numbers of people sustaining traumatic brain injury each year are staggering – 82,000 are sustained while participating in sports activities. Sadly, many of these injuries could have been prevented if the necessary safety measures would have been taken.

The days of urging athletes to “shake it off” after banging their head during a game must end. Preventing concussions or, at the very least, treating them appropriately, is as important as using the right hockey stick or soccer cleat.

Sincerely,

(Your organization’s president)
Dear Editor,

Americans are obsessed with technology. From nearly universal use of the Internet to the current craze over Palm Pilot personal organizers, Americans have been inundated with new electronic instruments designed to make their lives easier and more interesting.

One of the technologies quickly becoming commonplace is the use of cell phones. With airtime prices falling drastically and phones actually being given away for free by some stores, it is becoming much more affordable for people to buy and, therefore, use cell phones, particularly while driving around town. Unfortunately, it is too easy to forget that with the fun of talking whenever and wherever you want comes the responsibility of driving safely, a responsibility alarmingly ignored by many cell phone users.

Each day in the United States, there are an estimated 1,700+ collisions caused by improper cell phone usage. With those collisions comes $1 million in health care costs and $4 million in property damage and other costs. An unfortunate result of motor vehicle collisions is brain injuries. Car crashes continue to be the number one cause of brain injuries in this country, with nearly 50,000 people dying each year because of them.

Cell phones undoubtedly are excellent resources to have when a collision has occurred, as they enable emergency personnel to be alerted more quickly, therefore providing a greater chance to save lives in danger. However, when the use of cellular telephones in motor vehicles is associated with quadrupling the risk of a collision, the proper use of cell phones must be re-evaluated. Drive carefully—the life you save may very well be your own.

Sincerely,

(The president of your organization)
Sample Radio Public Service Announcements (PSAs)

**PSA #1**
Do you know someone with a brain injury?  
Did you know concussions are the most common form of mild brain injury?  
Have you or someone you know ever had a concussion?  
Then yes, you do know someone with a brain injury.  
To learn more about how you can prevent concussions and brain injury  
Contact the Brain Injury Association of…

**PSA #2**
About 4 million people live in Los Angeles  
About 3 million live in Chicago  
These are two of America’s biggest cities  
5.3 million Americans live with a disability caused by brain injury  
Pretty staggering, don’t you think?  
Learn more about brain injury by calling…

**PSA #3**
A brain injury doesn’t mean you’re a vegetable…  
A brain injury doesn’t mean you’ll be in a coma forever…  
A brain injury doesn’t mean you’re any less of a person…  
A brain injury may be life-altering  
But it doesn’t have to be life-ending  
Learn more about brain injury and how to prevent it by calling…

**PSA #4**
One backwards fall  
One bike ride without a helmet  
One accidental elbow to the head  
Is all it takes for a brain injury to occur  
To learn more about how to prevent brain injury  
Call the Brain Injury Association of…at…

**PSA #5**
Every 21 seconds someone sustains a brain injury  
One million people are treated for brain injuries each year  
More than 50,000 people die each year as a result.  
We’re working to change that.  
October is Brain Injury Awareness Month  
Get involved by calling…
**PSA #6**
Forgetting to fasten your seatbelt  
Bicycling or skateboarding without your helmet  
Shaking a baby  
Playing with a loaded gun  
Roughhousing on the playground  
Not watching where you walk…  
These are all ways brain injuries can occur  
Learn how you can protect yourself and your family  
Call…

**PSA #7**
In the 21 seconds it will take me to read this  
Somebody will have sustained a brain injury  
Brain injury can affect anyone.  
Learn more about it by calling…

**PSA #8**
It happens every 21 seconds  
Every 21 seconds a brain injury occurs  
It can happen to anyone:  
Young or old, black or white, rich or poor, male or female  
It is always unexpected  
It is always unwanted  
It is always life-changing…  
If it happens to you or someone you love,  
What do you do?  
Where do you turn?  
Where can you get help?  
Who will support you?  
What are your hopes for the future?  

Here is your answer…  
Call the Brain Injury Association of… at…

**PSA #9**
Your loved one sustained a brain injury.  
What do you do?  
Where do you turn?  
What happens now?  
What about the future?  
How can you help?  
For answers to your questions, contact your local Brain Injury Association at…
Sample Media Advisory

Contact:  
*Name of Media Point of Contact*  
(Contact Information: phone, e-mail, fax)

MEDIA ADVISORY

The Brain Injury Association of Somewhere, USA in partnership with BikeSafetyHelmet.com, will be giving away 100 bicycle helmets to area elementary school children at Rainbow Elementary School on Tuesday, October 13, 2000 as part of brain injury awareness month. Each year, approximately 350,000 children under age 15 go to hospital emergency departments with bicycle related injuries. Of these children, an estimated 130,000 sustain a brain injury. Medical research shows that 88% of cyclists’ brain injuries can be prevented by using a bicycle helmet.

WHO:  
City Mayor Rosemary Martin  
Rainbow Elementary School Principle Janet James  
CEO, BikeSafetyHelmet.com, Richard Alton  
President, Brain Injury Association Somewhere, USA Brian Samuels  
Program participants – 100 elementary school children ages five through nine

WHAT:  
Presentation on bicycle safety and how to select the right helmet. Demonstration on how to correctly wear bicycle helmets.

WHEN:  
Tuesday, October 13, 2000 at 1:30 p.m.

WHERE:  
Wilson A. Smith Auditorium, Rainbow Elementary School  
825 North Arnold Street, Somewhere, USA

STORY OPPORTUNITIES:

October is brain injury awareness month. Learn more about brain injury prevention through effective use of bicycle helmets.

Meet with the mayor and school principle to discuss the proactive plans to promote safety for children in the school district.

PHOTO/VIDEO OPPORTUNITIES:

One hundred children will be receiving bicycle helmets and shown the correct way to wear their helmets.
Sample Press Release

PRESS RELEASE

Hold for Release until October 3, 2000

CONTACT: (Name of Media Point of Contact)
(Contact Information: phone, fax, e-mail)

Harris Poll Shows Public Awareness of Brain Injury Is Very Low Given Nationwide Incidence

ALEXANDRIA, VA – Brain injury occurs every 21 seconds and sends more than one million individuals to hospital emergency rooms each year. Surveillance data from the Centers for Disease Control and Prevention (CDC) reveals that there are more than 5.3 million Americans—slightly more than two percent of the U.S. population—living with a disability as a result of a traumatic brain injury. Yet given this nationwide incidence, public awareness of brain injury—and the frequency with which it occurs—is very low, as the results of a recently conducted Harris Poll reflect.

“Brain injury occurs more frequently than breast cancer, AIDS, multiple sclerosis and spinal cord injury,” remarked Allan I. Bergman, President and CEO of the Brain Injury Association (BIA). “It is quite incredible, then, to see how few people believe this is the case. We have quite a task ahead of us in helping raise awareness of brain injury.”

Conducted by Harris Interactive, Inc., the poll surveyed a sample of 1,012 adults aged 18 or older regarding their awareness of brain and head injury. The poll found that one in three Americans say that they are not familiar with the term “brain injury.” Given the number of individuals living with a brain injury, only one in twenty individuals surveyed (5%) said that they themselves had sustained a brain injury.

--More--
Poll Finds Low Awareness of Brain Injury
2-2-2-2

Individuals surveyed were asked whether they thought brain injury occurred more or less frequently than breast cancer, AIDS, multiple sclerosis and spinal cord injuries. The poll found that two out of three adults (66%) believe that brain injuries happen less frequently than breast cancer, and half believe they happen less frequently than AIDS. However, the poll did reveal that adults are as likely to believe that brain injuries occur more frequently than spinal cord injuries or multiple sclerosis as to believe that they happen less frequently than either of these injuries/illness.

“There has been the belief that sustaining a brain injury doomed you to life in a persistent vegetative state or coma,” said James McDeavitt, MD, BIA Chairperson and Medical Director of the Charlotte Institute of Rehabilitation. “The results of BIA’s Harris Poll certainly prove this belief false, since the majority of those surveyed believe individuals sustaining a brain injury are capable of living ‘normal’ and productive lives. Hopefully this will help end some of the stigma surrounding brain injury, which leads individuals to deny they’ve sustained such an injury. Additionally, we certainly hope these results will lead to an increase in community living and support services provided to those who sustain brain injury, since the current level of service is quite low.”

One surprising result of the poll was that more than half of adults (56%) surveyed believe that when a person sustains a concussion, he or she sustains a brain injury. Concussions are the most common form of brain injury, yet recent media coverage of these injuries rarely, if ever, linked the term “concussion” with the term “brain injury.” This may explain, to some extent, the low number of individuals indicating that they had sustained a brain injury. Recent research of

--More--
Poll Finds Low Awareness of Brain Injury
3-3-3-3

brain scans, conducted by the UCLA Brain Injury Research Center, illustrated the significant changes the brain experiences after sustaining even one concussion. Concussion is the most common form of brain injury, with an estimated one million people sustaining a concussion annually.

The Brain Injury Association (BIA) conducted the Harris Poll as part of a five-year, cooperative agreement with the Health Resources and Services Administration (HRSA), a branch of the United States Department of Health and Human Services. Public awareness campaigns emphasizing how frequently brain injuries occur, how easily they can be prevented and the rich potential for life following brain injury will be launched during this five-year period, and follow-up polls to measure the effectiveness of these campaigns will be undertaken in years three and five of the agreement.

“Brain injury is the leading cause of death and disability among America’s youth,” McDeavitt said. “Almost all brain injuries—most often caused by motor vehicle crashes, falls, sporting accidents and violence—can be prevented. BIA is committed to increasing public awareness of this ‘silent epidemic’ significantly in the next few years, as well as emphasizing that those who sustain brain injuries are capable of living out their dreams.”

For a copy of the full Harris Survey, entitled Public Perceptions of Brain and Head Injuries, visit the Brain Injury Association’s web site at www.biausa.org.

Founded in 1980, the mission of the Brain Injury Association (BIA) is to create a better future through brain injury prevention, research, education and advocacy. BIA is the nation’s only nonprofit organization working on behalf of individuals with brain injury and their families, and has 46 chartered state affiliate partners across the country.

####

So You Wanna Be An Advocate...? • Brain Injury Association of America • 2001 • www.biausa.org • (703) 761-0750
Exercises

**Exercise One:** Advocacy efforts can be greatly furthered by effective use of the media. Think about your state, and begin to find answers to the following questions:

1. What is the newspaper with the largest circulation in your state?

2. What newspapers, and radio and television stations could you include in a list to develop as key media contacts?

**Exercise Two:** Next Sunday, be sure and buy a copy of the newspaper at your local newsstand. Try to identify some key reporters who might have an interest in brain injury…Does the paper have a reporter who works consistently on health issues? Political issues?

**Exercise Three:** Scan your local paper for a one-week time period and try and identify articles and issues that touch the lives or persons with brain injuries. Identify three pieces that your Association could respond to.
Grassroots and Media

Overhead Presentation
Writing the Script
**Exercise One:** The BIA has developed two draft pieces of legislation for use in this training and to be introduced at the legislature. A fact sheet has also been developed for each piece of proposed legislation. Follow these instructions:

- Break down into groups of 3-5 persons.
- Select one person from the group to be the recorder; select another person to be the reporter.
- Review the draft legislation and fact sheet assigned to your group.
- Develop a 3-5 minute script for a visit with a legislator, keeping in mind the following:
  1. What information about the group is important for the legislator to know?
  2. What are the key components of the legislation that you would like to convey?
  3. What action are you requesting from the legislature?
Glossary of Legislative Terms
Endnotes:


iv Projected annual reduced deaths if the State had a Primary law, presuming 45% effectiveness for use and a 17% rise in belt usage from enactment of a primary law. From: Targeting Injury Prevention Effectively, Flint, S.J., 2000. http://members.aol.com/targetinginjury/tipesb.htm