

People with Brain Injury are

# speaking out

About Quality in Services



*People with brain injury  
describe life as a journey to  
a new place, a different  
place filled with discoveries,  
and they begin to set goals  
and make decisions based  
on a new self.*

# speaking out

This is one of a series of booklets that reflect the views and opinions of people concerning the quality of services they receive. NCOR conducted several focus groups to find out what people were looking for in a support network and this is what they had to say. People featured in the Speaking Out series include:

- People with Brain Injury
- Parents of Children with Disabilities
- Adolescents with Disabilities
- People with Physical Disabilities
- Self-Advocates

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NCOR gratefully acknowledges the Brain Injury Association for their participation and opinions. It is their voices you hear.

Photography by Michelle Gienow

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# introduction

## As a person with brain injury:

- How do you define quality in services or supports?
- What outcomes or results do you expect from a quality service or support?
- What do you expect from a high quality service or support?



**T**he National Center on Outcomes Resources (NCOR), a division of The Council on Quality and Leadership, held a focus group and conducted individual interviews with persons living with traumatic brain injury. The purpose of these meetings was to learn from the real experts, people with brain injury, the answers to these questions on quality. The input received reflects the diversity and individuality of the participants. The employed survivor voiced different perspectives with brain injury, to the recently diagnosed young adults with traumatic brain injury struggling with education issues, to the seasoned advocate with brain injury.

This booklet presents the views of people with brain injury concerning the definition of quality in services and supports. It is critical to listen to what people with brain injury expect from quality services or supports. This will also give the reader a glimpse of the characteristics people with brain injury deem important when receiving quality services or supports.

Webster defines quality as a degree of excellence. Let's see what the experts in brain injury have to say.

# defining quality service or support

## Tailored to the Individual

Participants expressed a strong desire for services or supports that were tailored to the needs of each individual. They want to be sure that their dreams and vision for the future are an essential component of their plan for recovery and a life beyond brain injury.

*“I’d like a comprehensive scope of services provided in my home, or wherever I want. And I don’t want to feel that I am just getting the same prepackaged deal as everyone else. Make it about ME.”*

People change and traumatic brain injury causes dramatic changes in the lives of many people. Services need to be customized to people’s changing life patterns. That customization must be culturally sensitive and relevant.

The service or support should be delivered in a manner that respects individuality and takes into account the needs as well as the desires of that person.

## Choices and Options

People want control over their service delivery options. They want to have input into the design of their plan for supports.

In the restaurant business, presentation counts. People with brain injury

want quality services or supports presented with a vision for the future. They want customer service and responsiveness. They want professionals to listen to them.

People want their voices to be heard. They want multiple options for services or supports. People want to be able to make informed choices based upon objective information presented in a manner that they can understand.

## Outcome Based

A service that focuses on process is generally not valued. People want to be able to define satisfaction based upon the accomplishment of outcomes that are defined as important by the individual with brain injury. Many people said that it was important to evaluate how well the person responds to service and determine whether or not they are benefiting or making progress. The true value of a service or support is how well it works.

These outcomes are best accomplished with trained and competent professionals. They told us that the more practical the intervention, the more likely that it will lead to independence. The proposed outcomes need to be relevant to the individual.



**“My goals should be just that... MY choice.”**

## Support Groups

Many people with brain injury believe that an important component of a quality service or support includes support groups. People expressed the need and desire for peer support. People talked about the importance of role models and mentors to individuals with brain injury.

## Flexible

Services or supports that are flexible take into account that some people are ready for employment supports and others are not. Some people need residential services and others need in-home supports. Many people need and want support in the evenings. Others, because of fatigue, want their supports available in the morning.

# expectations and outcomes

## Acceptance

People with brain injury first need to accept their disability and then take responsibility for moving forward. People should recognize that they are survivors and they need to be an integral part of their own recovery.

We all have potential. Expectations and outcomes should be based upon this fact.

## Personal Growth and Independence

People link their definition of quality with their own experience of life and place in the community before their accident or before their fall or before their injury. Brain injury is a journey to a new place, a different place filled with discoveries.

*“...right now it’s important to me to be around others who have experienced what I’m going through...”*

As people transition from the acute phase of their injury to rehabilitation to possibly long-term services, supports, or adaptation, they often must redline their goals and their definition of independence. People indicated that services should maximize autonomy and assist

people to live an independent and productive life.

Independence is important but a high quality service or support would empower people to acquire skills that would allow them to be interdependent. None of us are totally independent. We depend on families, friends, community, as well as paid supports to be successful. Sometimes people need help to reconnect to their old circle or to connect with a new circle or supports. Services and supports should not solely focus on “fixing the person,” but rather, on teaching adaptations, reconnecting the individual to the community, and building capacity for interdependence and sharing.

## Dignity

Let the dignity of the individual be your guiding light. Everyone is capable of leading a productive life. It is critical that the staff believe that everyone has something to offer.

A person’s dignity is tied to self-esteem. Dignity and respect go together. A quality program is respectful of the dignity of each individual.

## Access

Services and supports for adults with brain injury are extremely limited in most states. People are not aware that services exist and they do not have information on how to access these



services. The existence of community or in-home supports is even more limited than facility-based rehabilitation services or supports.

Many people acquire their traumatic brain injury as adults. This eliminates their participation in many services or supports. Many states define eligibility for brain injury services if the traumatic brain injury occurred while the individual was still a child. Many adults who are injured and sustain a brain injury after the age of 22 have little or no access to public funded services.

People want to be able to easily access services when they need them. They also want to be able to discontinue services when it is no longer needed or no longer beneficial. They want access to services and supports soon after their injury and they want the option of an array of services and supports that are available long-term.

**“Before you ‘release’ me to the community, help me to build a support network.”**

# characteristics of quality



## One Stop Shopping

People want a seamless system that does not allow people to fall through the cracks. People with brain injury want a system of services and supports that is easy to understand, simple to navigate, and provides consistency in support. People want services that are available, accessible, and affordable.

Transition and continuity are essential components of a quality system of service or support. As people move from hospital care to a return to the community, we need to make sure services are available in the community.

## Dreams are Important

Although it is important to be honest and open with people with brain injury, it is also critical that we do not take away people's ability to dream. People's ability to dream may alter as a result of

**“I still have a vision for my future. Don't take that from me. Rather, help me make it clearer.”**

brain injury, but everyone has hopes and dreams. A quality program would help each individual to define or redefine his or her own vision for the future. Dreams include challenges and challenges define alternate solutions. It is important for professionals to be patient and understanding while continuing to challenge each person to reach his or her potential.

## Money

Services and supports for people with brain injury have been non-funded or significantly underfunded. Increased government spending to create and expand long-term services and supports for people with brain injury is needed. Defining quality is important but we need a comprehensive scope of services that are individually tailored. These services and supports should be structured to allow for maximum community participation and inclusion.

# what people with brain injury say

## About Quality in Services

**“Invite me to the table where decisions are made about me. Welcome me and adapt my environment so that I can function at my maximum potential.”**

**“What I think I have learned the most about quality is that one day I was sitting on the “good” side of the desk, the professional side; talking to folks who had disabilities and who had sustained brain injuries. And then a few days later, without really even knowing how it happened, I was sitting on the “patient” side of the desk. There is a very big difference between the two sides of the desk, and I have found that the professionals that I feel the best about seem most to understand that something could happen to them too and they could wind up on the patient side of the desk someday. It really affects how they treat and talk to us “patients.”**

**The people I've felt show the least quality in their interactions seem to be those who do not understand that it is only the grace of God or something like that that is keeping them on the “good” side of the desk, and who lack awareness that they are one unfortunate incident away from being a patient themselves someday. Not a happy thought, really a scary one, but highly determining of how you talk to and think about patients.”**

*“Please be honest about what you can and cannot offer me. If there are limits and caps, let’s negotiate priorities together. Take the time to know me as a person. Take the time to find out who I was before the accident. My self-esteem is tied to who I was yesterday and who I am today.”*

**“My own mission is educating people about TBI (Traumatic Brain Injury) and helping to improve the quality of life for people with TBI and their families. I try to help them have choices, options, challenges, and the opportunity to take risks if they so desire.”**

## About Quality of Life

**“Quality of life is freedom and independence.”**

**“Quality of life is having the opportunity to wake up in the morning with a purpose and the ability to pursue it.”**

**“Quality of life is having the opportunity and tools to achieve my goals.”**

*“The best quality services are those that are truly centered and crafted around the individual needs, hopes and dreams of the person being served. This means, no cookie-cutter, cookbook approaches that seek to mold someone into somebody else’s idea of who they should be and what they should do. The best measure of a quality outcome will always be determined by asking the individual involved if they have received the services and supports they needed to reach the goals they have set for themselves — and whether the program was flexible enough to adapt when their goals changed. In other words, genuine respect for autonomy and true self determination are at the heart of any quality program.” ~ Ralph William Shields*



## changing perspectives of quality



People's perspectives on quality change over time. These perspectives change when people become more knowledgeable about different types of services and supports. These perspectives change as people age and have different needs. These perspectives also vary based upon the severity of an individual's disability.

When a person is newly injured they have a perspective about quality that is naïve and always evolving. For many people the immediate response in the transition from able bodied to disabled is one of denial. The prognosis for brain injury is ever changing based upon many different variables. For many people it takes time to accept the diagnosis and the potential for long-term disability. Some people are hoping for miracles. Their focus is not quality services but rather, recovery.

Attitudes about quality vary according to people's age, disability, and culture.

**"With most injuries time heals, but with brain injury, time reveals."**

The perspective of quality is also influenced in the lives of children and young adults by their parents. People told us that the important thing about defining quality is to listen to your own heart.

# what can people with disabilities do to promote high quality services and supports?

## Internal Advocacy

People with brain injury need to learn how to give feedback to professionals and rehabilitation facilities. Survivors and families are too nice. They feel like they have to accept whatever is given to them. People need to find their voice and use it to give constructive feedback to improve systems.

People need training. People with brain injury told us about the importance of educating themselves and their families about quality issues in the disability service system.

People with brain injury need to become watchdogs. They told us about the need to monitor service providers and “keep their feet to the face.” They also made it clear that they believe that it is critical to hold providers accountable to quality for services.

The focus of all of our energies has been on holding providers accountable for facility-based services. It is important to expand the focus on accountability and quality to the schools. Many children with brain injuries do not have individualized education plans tailored to their specific cognitive processing needs. The schools have limited knowledge or expertise about how to effectively work with a child with brain injury.

Quality is not an issue. The lack of supports and expertise to deliver services is the issue in schools.

## External Advocacy

People with brain injury need to speak out in the community about the need to create and expand quality services and supports. People need to channel their voice using different media outlets such as newspaper human-interest stories and public awareness campaigns. The public needs to be educated.

The Americans with Disabilities Act affords all people with disability equal access. People with brain injury need to join cross disability coalitions to learn about their rights and access issues. As people become more aware of their rights they will be better able to define quality services and supports.

People with brain injury should listen to their guts. They should follow their intuition when it comes to defining quality services.

Many individuals are content with receiving a limited number of hours of service from a certain provider. Their focus may simply be access to ninety minutes a day of speech therapy or physical therapy in school, or five hours of respite a week, or four hours of personal care assistance a day. Other

individuals are more interested in what kinds of outcomes the service provides. Outcomes vary by the individual, as does the definition of quality.

There are many young adults with brain injury living in nursing homes and other segregated institutions. It is important to talk to those people about defining quality. They are often forgotten and left out. They went to the nursing facility in the first place because there were no other community options for long-term care.

As people redefine quality and push for the full implementation of the Americans with Disabilities Act, it will



be important to work with cross disability advocacy groups. People with brain injury need to learn how to “be a player at the table.”

Often there are varying levels of acute care available to newly injured people with brain injury. The problem

is that there are limited or no long-term care services except nursing homes. The issue is not quality; it is the lack of availability of services and supports.

As people find their voice they discover the importance of educating the legislature at the state and federal levels. Legislatures need to know that providers using public funds should be held accountable for outcome based quality services and supports.

## Self-Advocacy

People with disabilities want to have a voice. They want to be empowered to make informed choices about their lives. They want to be involved in the improvement of their own services and supports. They also want to be able to affect systems change.

Advocates told us that they want to have a strong voice, but some people need help to grow and mature. We need to work together across disabilities to enforce the provisions of the Americans with Disabilities Act.

Talk is one thing. People need to know how to cause a change in action to happen. People want to have training so they can more effectively self-advocate. Motivation and courage are important but we need to know how to connect with and work within the system to make it better.

As people join together to speak out in the community it is critical to have common goals, a sense of purpose, and a plan of action. In order to promote services and supports of high quality we need a strategy.

# characteristics of a quality provider

It was interesting to note the variety of characteristics put forth to define a quality provider. People with brain injury believe that a quality provider must have:

- Commitment and Passion
- Positive Attitude/Give People Hope
- Honest Communication
- Respect

Services for people with brain injury are very limited in many communities. Many young adults with brain injury are misplaced in segregated facilities. Many adults with traumatic brain injury are in prison, state mental health facilities, intermediate care facilities for the developmentally disabled, and in shelters. Traditionally, they have been misdiagnosed or have gone undiagnosed. Long-term care services and supports are non-existent in many places.

Medicaid waiver services for people with brain injury have only been developed in recent years. As of 1999, only

*“I understand that you want to protect me. But don’t just allow — encourage me to take risks — it’s the greatest fun in life.”*

21 states had traumatic brain injury waivers providing home and community-based services. Waivers were originally intended to redirect individuals from institutional settings to community

settings. Many people do not qualify for waiver funded services or the scope of the service is very limited.

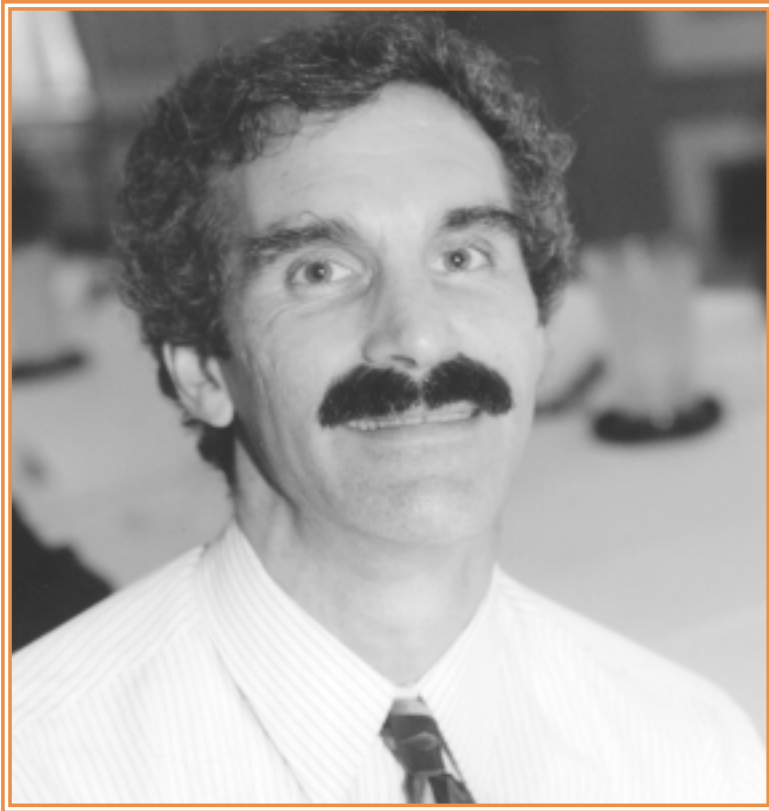
Brain injury often is thought of in terms of the medical model and acute care. The focus is on restoring bodily functions to maximum health. Providing functional rehabilitation and long-term supports is a relatively new field. Knowledge about effective interventions is still growing and evolving.

In a medical model, the control is vested with the physician. The source of power is within the medical team and the “patient” or person with the brain injury is not always an integral part of the team. This is changing as people with brain injury are finding their voice.

## Commitment and Passion

Staff need to be committed to providing support rather than attempting to be in control. Providers need to have a commitment for quality and excellence. The definition for quality needs to come from the customer. Outcomes rather than process should be the orientation for all staff.

This commitment and passion should be reflected in teams of caring professionals. Staff must be professional clinicians who are knowledgeable about best practices and current scientific



**“Give people hope.  
Ask them to aim high.”**

applied research related to rehabilitation and recovery. Staff have to have passion and love what they do.

Teams of staff should include the person with a disability as an integral part of the team. The purpose of the team should be guided by input of the needs and wants of the individual. There needs to be a commitment toward reintegration into the community. This can only be accomplished if the provider is culturally competent and understanding of the variety of needs of different families.

### **Positive Attitude**

A quality provider has a vision of an enhanced tomorrow for each person and their family. Supports should be offered to each individual with the expectation that progress is possible.

There is no good evidence about prognosis regarding brain injury and coma. Individual prognosis for people in a coma varies, so it is very important that staff have a positive attitude. People need hope. People need to be encouraged. People need to be able to dream. People need to be motivated.

Adaptation is also important. Technology is opening new avenues to independence. Hand held computers could be adapted for short-term memory loss. Global positioning devices can fill in for people who have lost their mapping capacity. Simple hand held tape recorders can serve as quick and easy reminders. The loss of some brain function can be relearned by other parts of the brain or can be substituted with available and affordable technology. It takes a creative provider to make a difference in someone’s life.

### **Honest Communication**

Communication is essential. A quality provider always keeps the person informed. They need to look at the person, not the disability. Some people with brain injury have been in a coma for some time. Communication is vital for people in a coma. Talk to them. Motivate them. Treat them as viable living human beings with vast potential. That’s who they are.

Quality providers will take the time to communicate. They will use strategies for open and interactive communication. Alternative forms of communication will be encouraged. Communication that is

**“Take the time to know me as a person.”**

appropriate to the individual’s neurological processing differences will always be a priority. Conversations will not be pressured or rushed. Summaries will be offered to assure that everyone is tracking at a similar pace.

## Respect

A quality provider will include the person in all decisions about that person. They do not issue false hopes and promises. Honesty drives the conversations and priorities and services are negotiated with the person. Technical assistance and adaptations are offered to help the person reach his or her full potential.

A quality provider will take the time to learn about the person behind the disability and will recognize the person as a special and unique individual with valid dreams and goals.

## Summary

What do people expect from quality services? They want services to provide choices, be accessible, and offer customized options to meet their specific needs. A quality service promotes independence and encourages people to dream and achieve their goals. People want to be listened to and be treated as unique individuals deserving of dignity and respect.



## resources

**Brain Injury Association of Alabama**

3600 8th Avenue South  
Birmingham, AL 35222  
205.328.3505

**Brain Injury Association of Alaska**

1251 Muldoon Road, Suite 32  
Anchorage, AK 99504  
907.338.9800

**Brain Injury Association of Arizona**

P.O. Box 44791  
Phoenix, AZ 85064  
602.952.2449

**Brain Injury Association of Arkansas**

P.O. Box 26236  
Little Rock, AR 72221  
501.224.5913

**Brain Injury Association of California**

P.O. Box 160786  
Sacramento, CA 95816-0786  
916.442.1710

**Brain Injury Association of Colorado**

4200 West Conejos Place, Suite 524  
Denver, CO 80204  
303.355.9969

**Brain Injury Association of Connecticut**

1800 Silas Deane Highway, Suite 224  
Rocky Hill, CT 06067  
860.721.8111

**Brain Injury Association of Delaware**

P.O. Box 95  
Middletown, DE 19709-0095  
302.537.5770

**Brain Injury Association of Florida**

North Broward Medical Center  
201 East Sample Road  
Pompano Beach, FL 33064  
954.786.2400

**Brain Injury Association of Georgia**

1447 Peachtree Street, NE, Suite 810  
Atlanta, GA 30309  
404.817.7577

**Brain Injury Association of Hawaii**

1775 S. Beretania Street, Suite 203  
Honolulu, HI 96826  
808.941.0372

**Brain Injury Association of Idaho**

P.O. Box 414  
Boise, ID 83701-0414  
208.336.7708

**Brain Injury Association of Illinois**

1127 South Mannheim Road, Suite 213  
Westchester, IL 60154  
708.344.4646

**Brain Injury Association of Indiana**

Mickolon Bldg., 1st Floor  
1525 N. Ritter Avenue  
Indianapolis, IN 46219  
317.356.7722

**Brain Injury Association of Iowa**

2101 Kimball Avenue, LL7  
Waterloo, IA 50702  
319.272.2312

**Brain Injury Association of Kansas**

1100 Pennsylvania Avenue, Lower Level  
Kansas City, MO 64105  
816.842.8607

**Brain Injury Association of Kentucky**

4229 Bardstown Road, Suite 330  
Louisville, KY 40207-3937  
502.493.0609

**Brain Injury Association of Louisiana**

217 West Buffwood Drive  
Baker, LA 70714-3755  
225.775.2780

**Brain Injury Association of Maine**

211 Maine Avenue, Suite 200  
Farmingdale, ME 04344  
207.582.4696

**Brain Injury Association of Maryland**

Kernan Hospital, 2200 Kernan Drive  
Baltimore, MD 21207  
410.448.2924

**Brain Injury Assoc. of Massachusetts**

Denholm Building  
484 Main Street, Suite 325  
Worcester, MA 01608  
508.795.0244

**Brain Injury Association of Michigan**

8619 W. Grand River, Suite I  
Brighton, MI 48116-2334  
810.229.5880

**Brain Injury Association of Minnesota**

43 Main Street, SE, Suite 135  
Minneapolis, MN 55414  
612.378.2742

**Brain Injury Association of Mississippi**

P.O. Box 55912  
Jackson, MS 39296-5912  
601.981.1021

**Brain Injury Association of Missouri**

10270 Page, Suite 100  
St. Louis, MO 63132  
314.426.4024

**Brain Injury Association of Montana**

University of Montana  
52 Corbin Hall, Room 333  
Missoula, MT 59812  
406.243.5973

**Brain Injury Association of Nebraska**

P.O. Box 124  
Gothenburg, NE 69138  
308.537.7875

**Brain Injury Association of New Hampshire**

109 North State Street, Suite 2  
Concord, NH 03301  
603.225.8400

**Brain Injury Association of New Jersey**

1090 King George Post Road, Suite 708  
Edison, NJ 08837  
732.738.1002

**Brain Injury Association of New Mexico**

11000 Candelaria Blvd., NE, Suite 113-W  
Albuquerque, NM 87112  
505.292.7414

**Brain Injury Association of New York**

10 Colvin Avenue  
Albany, NY 12206-1242  
518.459.7911

**Brain Injury Association of North Carolina**

P.O. Box 748  
Raleigh, NC 27602  
919.833.9634

**Brain Injury Association of North Dakota**

Open Door Center  
209 Second Street  
Valley City, ND 58072  
701.845.1124

**Brain Injury Association of Ohio**

1335 Dublin Road, Suite 217D  
Columbus, OH 43215-1000  
614.481.7100

**Brain Injury Association of Oklahoma**

P.O. Box 88  
Hillsdale, OK 73743-0088  
580.233.4363

**Brain Injury Association of Oregon**

1118 Lancaster Drive, NE, Suite 345  
Salem, OR 97301  
503.585.0855

**Brain Injury Association of Rhode Island**

Independence Square, 500 Prospect Street  
Pawtucket, RI 02860  
401.725.2360

**Brain Injury Association of South Carolina**

1030 St. Andrews Road  
Columbia, SC 29210  
803.731.0588

**Brain Injury Association of Tennessee**

1017 Water Place Way  
Knoxville, TN 37922  
615.264.3052

**Brain Injury Association of Texas**

1339 Lamar Square Drive, Suite C  
Austin, TX 78704  
512.326.1212

**Brain Injury Association of Utah**

1800 S. West Temple, Suite 203  
Salt Lake City, UT 84115  
801.484.2240

**Brain Injury Association of Vermont**

P.O. Box 8388  
Essex Junction, VT 05451  
802.872.9999

**Brain Injury Association of Virginia**

3212 Cutshaw Avenue, Suite 315  
Richmond, VA 23230  
804.355.5748

**Brain Injury Association of Washington**

16315 NE 87th, Suite B-4  
Redmond, WA 98052-3537  
425.895.0047

**Brain Injury Association of West Virginia**

P.O. Box 574  
Institute, WV 25112-0574  
304.766.4892

**Brain Injury Association of Wisconsin**

2900 N. 117th Street, Suite 100  
Wauwatosa, WI 53222  
414.778.4144

**Brain Injury Association of Wyoming**

111 West 2nd Street, Suite 106  
Casper, WY 82601  
307.473.1767

# these national organizations

can help families and people with disabilities find valuable resources  
in their community:

**Brain Injury Association**

105 North Alfred Street  
Alexandria, VA 22314  
800.444.6443  
703.236.6000  
Fax: 703.236.6001  
www.biausa.org

**Brain Trauma Foundation/  
Aitken Neuroscience Institute**

523 East 72nd Street, 8th Floor  
New York, NY 10021  
212.772.0608  
Fax: 212.772.0357  
www.aitken.org

**Clinical Trials in Head Injury**

www.ninds.nih.gov/news\_and\_  
events/headinjurywkshp.htm

**Coma Recovery Association, Inc.**

807 Carman Avenue  
Westbury, NY 11590  
516.997.1826  
Fax: 516.997.1613  
www.comarecovery.org

**Family Caregiver Alliance**

690 Market Street, Suite 600  
San Francisco, CA 94104  
415.434.3388  
800.445.8106  
Fax: 415.434.3508  
www.caregiver.org

**Head Injury Hotline**

212 Pioneer Building  
Seattle, WA 98104-2221  
206.621.8558  
Fax: 206.624.4961  
www.headinjury.com

**MEDLINEplus:**

**Head and Brain Injuries**  
www.nlm.nih.gov/medlineplus/  
headandbraininjuries.html

**National Center for Injury  
Prevention and Control**

Mailstop K65  
4770 Buford Highway NE  
Atlanta, GA 30341-3724  
Phone: 770.488.1506  
Fax: 770.488.1667  
www.cdc.gov/ncipc

**National Family Caregivers  
Association**

10400 Connecticut Ave., #500  
Kensington, MD 20895-3944  
800.896.3650  
Fax: 301.942.2302  
www.nfcacares.org

**National Institute of  
Neurological Disorders  
and Stroke**

(NINDS)  
NIH Neurological Institute  
P.O. Box 5801  
Bethesda, MD 20824  
800.352.9424  
www.ninds.nih.gov

**The National Rehabilitation  
Information Center**

(NARIC)  
Browse NARIC Databases:  
Brain Injuries  
www.naric.com/naric/  
search/t04.html

**National Resource Center for  
Traumatic Brain Injury**

Virginia Commonwealth  
University  
Department of Physical  
Medicine and Rehabilitation  
P.O. Box 980542  
Richmond, VA 23298-0542  
804.828.9055  
Fax: 804.828.2378  
neuro.pmr.vcu.edu

**National Stroke Association**

9707 East Easter Lane  
Englewood, CO 80112-3747  
800.STROKES (787-6537)  
303.649.9299  
Fax: 303.649.1328  
www.stroke.org

**The Perspectives Network**

P.O. Box 1859  
Cumming, GA 30028-1859  
Voice/Fax: 770.844.6898  
www.tbi.org

**Recovery Awareness  
Foundation**

P.O. Box 98  
Atlantic, VA 23303  
www.home.tbinet.org/raf

**Rehabilitation of Persons with  
Traumatic Brain Injury**

Current Bibliographies in  
Medicine 98-1  
National Library of Medicine  
www.nlm.nih.gov/pubs/cbm/  
tbi.html

**Research and Training Center  
on Community Integration of  
Individuals with Traumatic  
Brain Injury**

Department of Rehabilitation  
Medicine, Box 1240  
Mount Sinai School of Medicine  
One Gustave L. Levy Place  
New York, NY 10029  
888.241.5152  
www.mssm.edu/tbinet

**Traumatic Brain Injury  
Model Systems**

www.tbims.org



The National Center on Outcomes Resources (NCOR) is the research division of The Council on Quality and Leadership in Supports for People with Disabilities and provides leadership in outcomes research, analysis and dissemination. NCOR is a clearinghouse and information resource on outcomes data on all aspects pertaining to people with disabilities, with a special focus on developmental disabilities.



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