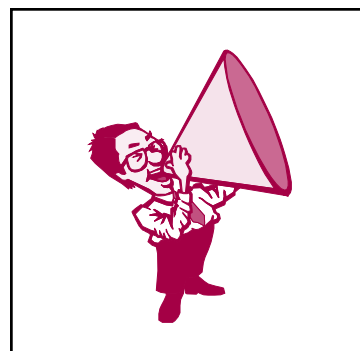


# A GUIDE TO BEING HEARD

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## **Brain Injury Association of New York State**

10 Colvin Avenue

Albany, NY 12206-1242

Telephone: (518) 459-7911 • Fax: (518) 482-5285

Family Help Line: (800) 228-8201

E-mail: [info@bianys.org](mailto:info@bianys.org) • Web Site: [www.bianys.org](http://www.bianys.org)

how to  
advocate  
for  
your child  
with  
traumatic  
brain  
injury



## PARENTS - YOUR CHILD'S BEST ADVOCATE

This booklet is designed for the family and friends of a child who has experienced a brain injury. This booklet will help you understand ways to care for and support your child. You can also contact the Brain Injury Association of New York State to ask questions about any information in this booklet, or any other questions about your child's brain injury. A description of the Association and the contact information can be found on page 9.

One person who can be extremely helpful to you is the Brain Injury Association of New York State's FACTS Coordinator. "FACTS" stands for the Family, Advocacy, Counseling and Training Services program of the Association. The FACTS Coordinator is a knowledgeable individual who can provide you with information about brain injury and community resources as well as support. You can find out the name of the FACTS Coordinator in your area by contacting the Association.

You know more about your son or daughter than anyone else. And, you have the ultimate commitment to and responsibility for your child. While staff and programs change, parents remain a constant in the life of a child with a brain injury.



## GETTING STARTED

Parents really act as "service coordinators" within the family hub. You are the inner core of the wheel, while services are the spokes that extend or radiate outward. The purpose of this booklet is to assist **you**, the parent, as the primary advocate for your child.

An advocate is defined as, "one who pleads the cause of another..." It is important for the family step into the role of advocate. Knowledge and effective advocacy strategies will increase the likelihood that you will successfully obtain services for your child. There is nothing easy about this, but creating a positive collaboration with professionals and service providers will greatly benefit your child and your family.

What follows are some skills and strategies that can help you become an effective and assertive advocate for your child.

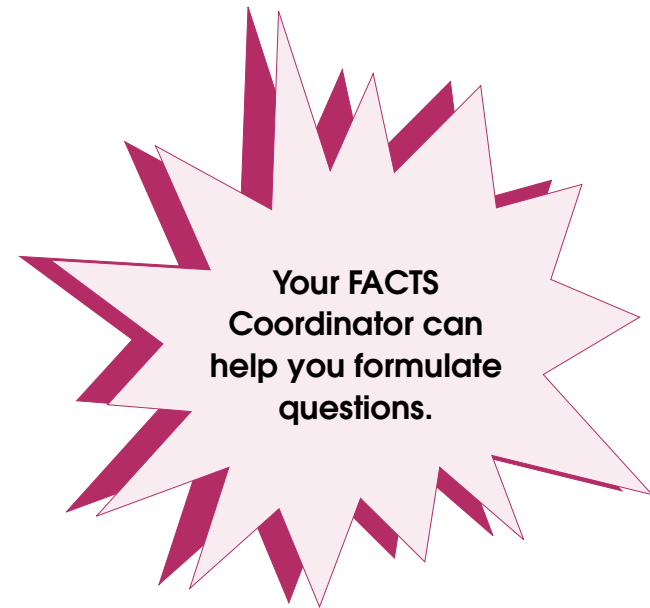
## ASK, ASK, ASK

Advocating for your child with a brain injury is a new experience. There is a lot of information you need to learn so you can advocate effectively. Much of the information may be new and unfamiliar to you. These hints will help you stay focused and organized.

- ◆ Become as educated as possible about brain injury generally, and your child's needs in particular. Through your experiences in medical and rehabilitation settings, networking with other parents, and working with a variety

of professionals in the brain injury field, you will learn a great deal about your child's needs and the strategies that can be helpful. In reality, parents are in the position to have a realistic view of the "whole" child, and can provide suggestions for behavioral, social, and cognitive approaches that are invaluable to any professional team.

- ◆ Learn about your child's rights, and make sure that your child receives all services and supports to which he or she is entitled.
- ◆ Continually ask questions until you get answers. **YOU** are the expert on your child and need to understand the circumstances surrounding the injury and subsequent treatment and education. Search out both professionals and nonprofessionals for answers to your questions.



## COLLABORATION

Try to find a way to work collaboratively with all medical, school, and rehabilitation personnel. For a variety of reasons, these processes sometimes break down. The suggestions below can help keep things moving.

- ◆ Try taking the perspective of the other person. Understand the position taken by another and appreciate the good intentions that can motivate behavior.
- ◆ Emphasize the positive.
- ◆ Say thank you when people are helpful.
- ◆ If the relationship isn't working, find another professional with whom you feel you can work better.
- ◆ Talk to someone with more authority in the organization or agency.
- ◆ Ask other professionals to intervene and help resolve the impasse, when you have no place to go.
- ◆ If all else fails, consider going outside the system for support. Some suggestions include: political (lobbying/legislative changes), legal action, and public action (media coverage). Another option is to contact your local legislator. They often are able to help families negotiate with the various bureaucracies involved.

## MEETINGS

Participating in meetings is an important aspect of your advocacy. Here are some tips for effective meetings.

- ◆ Stay on top of the process. Keep a journal of correspondence, meetings, and phone calls. Include the date, type of contact, person's name, title, and summary of areas discussed. In addition, keep copies of all materials you received from professionals and providers. Stay organized!
- ◆ When preparing for a meeting, have the following information:
  - date, time, and place of meeting
  - directions if you are unsure of where to go
  - name and affiliations of all participants
  - purpose of meeting and relevant points of information, decisions or areas of disagreement
- ◆ Consider submitting a written agenda prior to a meeting. This agenda would include, points you wish to have discussed; questions you'd like answered and decisions you'd like made, so that all participants come to the meeting with ideas and strategies. Make sure that the agenda for the meeting allows time for your items to be discussed.



- ◆ At the end of meetings, make sure that decisions, next steps, and deadlines are summarized and agreed upon by all.
- ◆ Take notes at all meetings. When possible, tape record meetings. This will enable you to listen to them once again in a more relaxed fashion.
- ◆ Have professionals explain the purpose and conditions of all suggested testing and assessments, and identify who will be doing the testing.
- ◆ Find a "buddy" or partner. Some parents find it helpful to share all information and meetings with another person. Many people think of their spouses, but it can be anyone you can rely on. A "buddy" can:
  - help you remember things when you are tense nervous, or upset
  - be more objective
  - provide another ear for listening and problem solving
  - help your child if you are not available



## EDUCATION

Your child's education is one of your top priorities. Ensuring educational opportunities is extremely complex. The Brain Injury Association of New York State has many publications that can help you negotiate this system.

- ◆ When developing your child's educational plan, keep in mind that most educators lack extensive knowledge about brain injury. You are the best source of information about the impact of brain injury and strategies for assisting your child to be successful in the school setting. Parents also have access to written materials and resources, as well as personal knowledge about their child's brain injury.
- ◆ Before your child returns to school following a brain injury, try to arrange an educational session on brain injury for all staff, including non-educational staff such as janitors, coaches, and bus drivers. You might also consider a program for your child's classmates.

**Discuss your  
child's return to  
school re-entry  
with your FACTS  
Coordinator.**

## TAKE CARE OF YOURSELF

It is important to remember that **you are not alone**. Try to take advantage of community resources and other parents who have had similar experiences.

- ◆ To be an effective advocate, it is important to remember to take care of yourself. It is easy to burn out from all the stress and exhaustion. Pay attention to your own stress and take steps to nurture yourself. This may involve seeking the counsel of friends or a clergy member; it may mean sticking to an exercise regimen; or it may mean that you occasionally take a break from being an advocate to step back and re-group before beginning again.
- ◆ Join self-help, support groups and advocacy groups. These groups offer families a supportive environment in which members can share their feelings as well as their knowledge. For families, joining a group is an important self-help decision and can help you gain confidence in your own abilities to overcome difficult obstacles.
- ◆ Many groups also help with problem-solving. Group members work together to identify, discuss and find ways to change laws and influence policies that affect their lives directly.



## RESOURCES

A key skill needed to be an effective advocate is becoming informed and having a network for support and information. The following resources may be helpful to you.

### Brain Injury Association of New York State

10 Colvin Avenue  
Albany, NY 12206-1242  
518-459-7911 VOICE, TTY  
518-482-5285 FAX  
Family Helpline 1-800-228-8201  
E-mail: [info@bianys.org](mailto:info@bianys.org)  
Web site: [www.bianys.org](http://www.bianys.org)

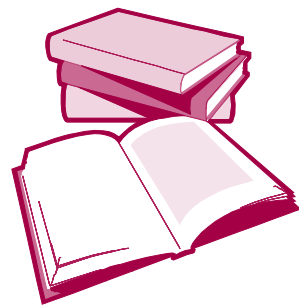
The Brain Injury Association of New York State is a statewide non-profit membership organization that advocates on behalf of individuals with brain injury and their families, and promotes prevention. Established in 1982, the Brain Injury Association of New York State provides education, advocacy, and community support services that lead to improved outcomes for children and adults with brain injuries and their families.

The Brain Injury Association of New York State also offers a toll-free family helpline, chapters and support groups throughout the state, prevention programs, mentoring programs, a speaker's bureau, and an information clearinghouse of videos, publications, books, periodicals and other resource materials. The Association plays a central role in the development of public policy on the state and local level. The Brain Injury Association of New York State is the state affiliate of the Brain Injury Association of America.

## **The Family Advocacy, Counseling and Training Services**

**Program (FACTS)** of the Brain Injury Association of New York State is a support service for individuals who sustained a brain injury and their families. FACTS Coordinators are located throughout the state and are able to provide services in each county. The FACTS program provides persons with brain injury and their families with the following free services.

- ◆ supportive counseling and on-going emotional support for the individual and family;
- ◆ assistance in locating appropriate services in the community;
- ◆ information and linkage with state and local systems;
- ◆ education, advocacy, and training of persons with brain injury and their families regarding TBI;
- ◆ assistance with the development of brain injury support groups;
- ◆ assistance with bringing your child back from out-of-state and the prevention of out-of-state placements; and
- ◆ outreach and training to local service providers such as hospitals and schools regarding TBI, and assistance with the development of services for persons with TBI.



## **NEW YORK STATE AGENCIES**

New York State agencies provide a wide range of services to individuals with disabilities. Some of the agencies listed below have special programs for persons with brain injury and their families. You will also find information about financial assistance, educational/vocational resources, advocacy, and legal counseling.

### **New York State Office of Mental Retardation and Developmental Disabilities (OMRDD)**

Statewide TBI Coordinator  
44 Holland Avenue  
Albany, NY 12229  
518-474-8652  
[www.omr.state.ny.us](http://www.omr.state.ny.us)

OMRDD serves individuals with developmental disabilities resulting from traumatic brain injury sustained before the age of 22. OMRDD operates district offices known as Developmental Disabilities Service Offices (DDSOs) throughout New York State.

### **New York State Department of Health (DOH)**

Bureau of Long Term Care Brain Injury Program  
Office of Medicaid Management  
1 Commerce Plaza  
Albany, NY 12260  
518-474-6580  
[nyhealth@health.state.ny.us](mailto:nyhealth@health.state.ny.us) (e-mail)  
[www.health.state.ny.us](http://www.health.state.ny.us) (web site)

Provides many essential services for individuals with brain injury and administers the Home and Community Based Services TBI Medicaid Waiver.

## **New York State Education Department Office of Vocational and Educational Services for Individuals with Disabilities (VESID)**

Special Education Policy and Quality Assurance  
New York State Education Department  
One Commerce Plaza  
Albany, NY 12234  
800-222-5627 • 518-474-2714  
[www.nysed.gov/](http://www.nysed.gov/) (then click on VESID)

VESID promotes educational equity and excellence for students with disabilities, and advocates for the rights and protections to which they are entitled.

## **The Commission on Quality of Care (CQC)**

401 State Street  
Schenectady, NY 12305  
800-624-4143 • 518-381-7000

Serves people with mental disabilities and their families by providing independent oversight of the quality and cost effectiveness of services provided by all mental hygiene programs in New York State. The Commission provides legal and non-legal advocacy services to persons with disabilities to assist them in obtaining the services and protections of federal and state laws.

## **New York State Office of Advocate for Persons with Disabilities**

One Empire Plaza, Suite 1001  
Albany, NY 12223-1150  
800-522-4369 • 518-473-6005 (Fax)  
[information@oapwd.state.ny.us](mailto:information@oapwd.state.ny.us) (e-mail)  
[www.advoc4disabled.state.ny.us](http://www.advoc4disabled.state.ny.us) (web site)

This agency's mission is to ensure that people with disabilities have every opportunity to be productive and participating citizens through access to emerging technology and information, legislation, and state policy development.

## **New York State Crime Victims Board (CVB)**

845 Central Avenue  
Albany, New York 12206  
Phone: 518-457-8727 • 1-800-247-8035  
Web Site: [www.cvb.state.ny.us](http://www.cvb.state.ny.us)

This agency provides compensation to innocent victims of crime for certain unreimbursed expenses casually related to their victimization; funds local community-based programs to provide direct services to crime victims and advocates for the right and benefits of crime victims in New York State.

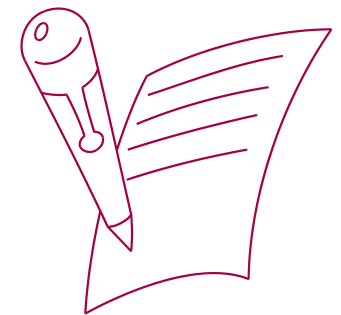
## **OTHER RESOURCES:**

### **Resources for Children with Special Needs**

200 Park Ave. South, Suite 816  
New York, New York 10003  
Telephone: 212-677-4650  
Web Site: [www.resourcesnyc.org](http://www.resourcesnyc.org)

### **National Information Center for Children and Youth with Disabilities (NICHCY)**

P.O. Box 1492  
Washington, DC 20013  
Telephone: 1-800-695-0285 (voice/TTY)  
Fax: 202-884-8441  
E-mail: [nichey@aed.org](mailto:nichey@aed.org)  
Web Site: [www.nichcy.org](http://www.nichcy.org)





**Parent Advocacy Coalition for Education Rights (PACER Center)**

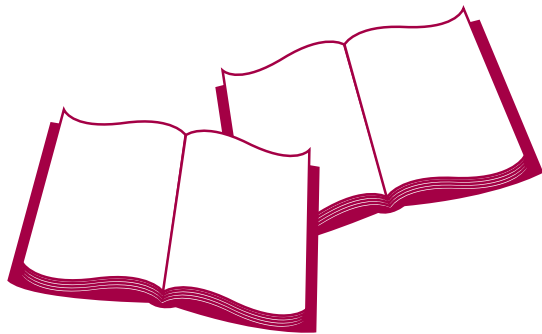
8161 Normandale Blvd.  
Minneapolis, MN 55437  
Telephone: 888-248-0822  
Fax: 952-838-0199  
E-mail: [pacer@pacer.org](mailto:pacer@pacer.org)  
Web Site: [www.pacer.org](http://www.pacer.org)

**National Early Childhood Technical Assistance Services (NECTAS)**

137 East Franklin Street, Suite 500  
Chapel Hill, NC 27514-3628  
Telephone: 919-962-2001  
TDD: 877-574-3194  
Fax: 919-966-7463  
E-mail: [nectas@unc.edu](mailto:nectas@unc.edu)  
Web Site: [www.nectas.unc.edu](http://www.nectas.unc.edu)

**Lash and Associates Publishing/Training**

708 Young Forest Drive  
Wake Forest, N.C. 27587  
Telephone: 919-562-0015  
Web Site: [www.lapublishing.com](http://www.lapublishing.com)



**Brain Injury Association of America**

8201 Greenshore Drive, Suite 611  
McLean, Virginia 22102  
Phone: 800-444-6443  
Web Site: [www.biausa.org](http://www.biausa.org)

The mission of the Brain Injury Association of America is to create a better future through brain injury prevention, research, education and advocacy. Through its national office and network of state affiliates, BIAA provides leadership and advocacy on policy and treatment issues affecting individuals with brain injury and their families, information and education, public awareness and education and research. The interactive web page provides extensive information about all aspects of brain injury.

**New York State Independent Living Council, Inc.**

111 Washington Avenue, Suite 101  
Albany, New York 12210  
518-427-1060 VOICE/TTD  
1-888-469-7452 (NY only) • 518-427-1139 FAX  
E-mail: [nysilc@global2000.net](mailto:nysilc@global2000.net)  
Website: [www.nysilc.org](http://www.nysilc.org)

A network of 35 community- based advocacy organizations in New York State which offers benefits advisement, peer support, independent living skills training & legal assistance to persons with disabilities.

