

LEARNet: Living Education and Resources Network



www.projectlearnnet.org

A Resource Tool for Parents, Educators, and
Clinicians of Students with Brain Injury





About the Brain Injury Association of New York State

The Brain Injury Association of New York State (the Association) is a statewide nonprofit membership organization that advocates on behalf of individuals with brain injury and their families, and promotes prevention. Established in 1982, the Association provides education, advocacy and community support services that lead to improved outcomes for children, adolescents, and adults with brain injury and their families. The Brain Injury Association of New York State also provides a toll free Family Help Line, chapters and support groups throughout the state, prevention programs, mentoring programs, speaker's bureau, a video lending library and publications library. The Association plays a central role in the development of public policy on the federal, state, and local level. The Brain Injury Association of New York State is the chartered state affiliate of the Brain Injury Association of America.

How to contact the Association:

Address: 10 Colvin Avenue
Albany, New York 12206-1242

Phone: (518) 459-7911

Fax: (518) 482-5285

Toll Free Family Help Line: (800) 228-8201

Email Address: info@bianys.org
projectlearnnet@bianys.org

Website: www.bianys.org
www.projectlearnnet.org

Project Consultants

Mark Ylvisaker, Ph.D

Mary Hibbard, Ph.D, ABPP



TABLE OF CONTENTS

Introduction..... p3

A Word about the Family Advocacy, Counseling & Training Services Program (FACTS). p3

LEARNetp4

 Overview of the Problem Solving System..... p4

 Step 1: What Problems Have You Seen? p5

 Step 2: Brainstorming the Possibilities p6

 Step 3: Exploring and Testing the Explanationsp6

 Step 4: Interventions & Supportsp7

Additional Components p8

Final Comments p9

Publicationsp9

New York State Agencies.....p10

Other Resourcesp12





INTRODUCTION

For years, educators and parents have reported that helping children and adolescents with brain injury is a challenge that requires creativity and often the consulting help of a specialist. In 2005, the Brain Injury Association of New York State was awarded a grant from the New York State Developmental Disabilities Planning Council to create and sustain competency for families and school staff to respond to the challenges of children with brain injury and other neurological impairments at home and at school by establishing an interactive, user-friendly web-based information and resource program, LEARNet. LEARNet, found on the Internet at **www.projectlearn.net**, has been recognized across the state and beyond for its utility in providing educators and families with invaluable information designed to improve the educational outcomes for students with brain injury.

This manual was created to help you make the most your experience using the LEARNet Problem-Solving System found at **www.projectlearn.net**. For additional help using LEARNet, please contact the Brain Injury Association of New York State or the local **Family Advocacy, Counseling and Training Services (FACTS) Coordinator**. Contact information can be found in the front of this manual, by phoning the Association, or by visiting our websites at **www.projectlearn.net** or **www.bianys.org**.

A Word about the Family Advocacy, Counseling & Training Services Program (FACTS)

The FACTS Program is a free service offered by the Brain Injury Association of New York State, funded by the New York State Office of Mental Retardation and Developmental Disabilities. The Association employs several FACTS Coordinators throughout New York State who can assist your family with:

- understanding and navigating the current system of services available in NYS
- offering support throughout the Individualized Education Plan (IEP) process, teaching you how to communicate with the Committee on Special Education (CSE)
- training service providers and educators to understand the impact of brain injury and brain injury prevention
- connecting you to community support groups
- linking you to rehabilitation services in the community and throughout NYS
- helping you access NYS Medicaid Waiver and other benefit programs



If you or a family member was injured prior to age 22 and you live in New York State, you are eligible for FACTS services. Contact the FACTS Coordinator in your region today by calling the Association at (800) 228-8201 or going to the website at www.bianys.org.

LEARNET

Overview of the LEARNet Problem Solving System

The heart of the LEARNet website is the problem-solving system. Many of the issues, or troubling behaviors, families and educators encounter with students with a brain injury may be explained in **several** different ways. We do not know how to help a student until we understand the problem. Often, understanding the problem requires considering several possibilities and putting them to a test in the student's real world. This is what LEARNet is about.

This way of thinking about how to help students is really common sense and common practice in many fields. For example, let's say there is a clicking sound coming from your car engine. You take your car to a mechanic. Your mechanic will say something like, "It could be A, B, or C; let's start with the simplest, cheapest; try some additive in your gas for a week and see if that takes care of it. If not, let me know and we will explore possibility B. We'll hope it's not C- that would require major work." You hope your mechanic won't say, "I'm pretty sure it's a problem with your valves. I'll have to pull the engine and the work will cost about \$2000."

Or if you go to your physician with a complaint about a pain in your stomach, your physician likely will say something like "the problem could just be some intestinal gas, or it could be a variety of other possibilities, but let's hope it's a simple matter of gas. Why don't you try an antacid for a week and then let me know if you are still feeling the discomfort. If you are, we can explore other possibilities." You don't want your physician to say, "I think it's probably stomach cancer, I'll schedule you for immediate surgery."

So, although this process can seem complex or intimidating, it is really just common sense applied in a systematic way. It's the best process for identifying effective interventions, instructional strategies, and supports for students with disability who have tricky or complex problems.

Let's examine an example:

Many students with brain injury show a marked inconsistency in their performance and behavior from day to day, sometimes even hour to hour. Naturally, this is troubling for teachers, parents and therapists, and raises important questions about how best to teach and support the student.



Why might there be such inconsistency?

1. **Medical possibilities**- perhaps fluctuating levels of medication have an impact on performance (i.e. maybe there are undiagnosed seizures).
2. **Cognitive possibilities**- perhaps the student has times when the brain systems supporting attention or supporting retrieval are weak.
3. **Self-regulation possibilities**- perhaps the student cannot inhibit certain negative emotions on some days. Perhaps the brain systems supporting initiation or organization are weak on some days.
4. **Behavioral possibilities**- perhaps the student feels oppositional on some days, or perhaps manipulative.
5. **Emotional possibilities**- perhaps the student's level of sadness or loneliness or depression or anxiety varies from day to day and significantly affects performance.

It is easy to understand that treating the problem as though it is one issue, say a behavioral problem, when in fact it is another issue, say a medical or cognitive problem, would result in ineffective treatment and a failure to serve the student well. Thus, it is critical that there be a method for sorting out the possibilities and systematically determining which of those possibilities is in fact the underlying problem or at least a part of the problem. This is what LEARNet does.

The process has four steps and three additional critical features (explained in step 4)

Step 1: What problems do you see? This is a clear statement of the presenting problem in simple observational terms.

The first page of LEARNet contains a list of problems that are frequently observed and reported by educators and families of students with brain injury. These problems are stated in simple observational terms. What you actually see, **NOT** your interpretation of what you see.

For example, if a student fails to comply with academic instructions and tasks, the statement of the problem should be "*the student often does not do what he is told to do and does not begin or does not finish academic tasks.*"

NOT: "The student is noncompliant" or "the student is manipulative" or "the student does not comprehend instructions" or "the student is depressed". These are all possibilities, but they are only potential explanations for what you see; potential hypotheses or ideas. They are not the problematic behavior that you actually observe.



The main point is to begin with a simple description of what you actually see, what you observe, not what you think the explanation is. You do not see manipulation or oppositionality or lack of comprehension or depression or anxiety.

Step 2: Brainstorming about possible explanations for the problematic behavior that is observed

If you click on one of the problems listed on the first page of LEARNet, you will be taken to a list of possible explanations for the problematic behavior. In most cases, there are medical, cognitive, behavioral, and emotional possibilities. You should consider each and decide which of the possibilities may be operating in the situation at hand. **Remember that in many cases, there is more than one contributor to the problem. Therefore, it is likely that more than one type of intervention or support should be used.**

Step 3: Systematic exploration or testing of alternative possible explanations for the identified problem.

If you click on one of the possible explanations for the observed problem, you will be taken to a page that offers practical strategies for determining if that possibility is really part of the explanation for the problem. In some cases, the strategy is a referral to a relevant specialist. For example, if seizures are suspected, then a referral to a doctor is the most appropriate course of action.

However, in many cases, the most effective exploration involves varying some of the conditions in the student's everyday school or home routines and determining what difference that makes.

For example:

It is observed that student does not comply with instructions. It is hypothesized or guessed that the student does not comply with instructions because he/she does not understand the instructions.

We test this possibility by:

1. Offering instructions in the standard way with no special supports
2. Offering special supports with instructions, for example, graphic support for the instructions
3. See if it makes a difference. If it does then there is support for the conclusion that lack of comprehension is a contributor to the observed failure to comply, and appropriate changes or supports can be added to the student's academic routine.



This is the template used for exploring possible explanations for observed problems

1. Try the activity
2. Try it with special supports or interventions
3. Did it work?

Step 4: Well thought-out and evidence-based interventions and supports associated with the results of the problem solving, and testing the possibilities you have discovered.

If it emerges in Step 3 that one or more of the possible explanations for the problematic behavior is a real contributor to the problem, you will be directed to click on links to pages called "Tutorials". These pages will offer suggestions for interventions or supports that can be used to address the problem.



Each of these Tutorials has three critical features:

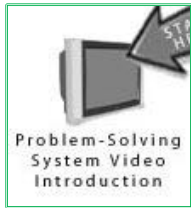
1. **What are the issues?** For example, if it is determined that the student has difficulties in school or at home as a result of organizational problems, you would click on the link to the tutorial on **Cognitive Organization**. Section 1 of that tutorial will have a brief explanation of cognitive organization and how organizational difficulties manifest themselves.
2. **What does the issue have to do with brain injury?** The second section connects the issue to brain injury. For example, in the case of cognitive organization, the part of the brain involved in organizational processing is identified and its frequency of involvement in brain injury is highlighted.
3. **What are the main themes in intervention and support?** This section lists a variety of strategies that are known to be helpful for students with the identified problem. These strategies are what most parents and educators are interested in. However, going through the process of systematically identifying what the actual problem is should not be neglected unless you are very confident that you have an accurate understanding of that problem.

In many cases, several of these tutorials will be useful for a given complex problem. In addition, tutorials can be accessed on the website without going through the first three steps of the problem-solving process. Several of the tutorials also include a **video illustration** of selected intervention strategies and some end with a summary of evidence supporting the intervention and support suggestions.



Additional Components

Take your time, remember that LEARNet is a process, explore the other menu items and information available to you on the LEARNet website. They include:



Video Welcome to LEARNet

There are two brief videos presented by Judith Avner, Executive Director of the Brain Injury Association and Dr. Mark Ylvisaker.



This section provides an overview of Project LEARN: Living Education and Resources Network, a program funded by the New York State Developmental Disabilities Planning Council. Learn about the grant activities that supported the development of the LEARNet website.



A link is provided that directs users to a comprehensive online dictionary of brain injury related terms and definitions.



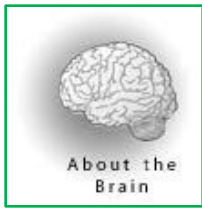
This section provides a listing of state and local resources as well as a comprehensive listing of helpful websites, books, and articles related to pediatric brain injury and school-reentry.



Users will find links to special events and conferences designed to provide training and support to parents, educators, and other professionals working with individuals with brain injury.



This section offers users information on how to contact the Brain Injury Association of New York State in the event that they have questions or require additional information. The system of support includes the Brain Injury Association of New York State's Family Advocacy, Counseling and Training Services (FACTS) program, educators, and LEARNet team consultants.



About the Brain

This section provides general information and links to other websites that explain how the brain works and what happens when someone sustains an injury to the brain.



For Kids

This section offers information for students living with brain injury. We have included a link to a website that provides kid-oriented information about how the brain works. Also included is resource and support information geared toward the needs of students with brain injury.



For Parents

This section provides resource information on a number of relevant topics designed to support parents of a child with brain injury. Many of the topics covered were developed directly in response to family focus groups that were conducted across New York State during the first year of the Project LEARN grant. Family groups discussed the problems, issues, and questions they have related to the responsibility of raising a child with brain injury.



For Teachers

This section provides resource information for teachers. Examples of material and resources included in this section relate to the Individuals With Disabilities Education Act (IDEA) and No Child Left Behind legislation, and communicating effectively with parents.

FINAL COMMENTS

The LEARNet system is a process. It can be challenging to switch back and forth throughout the website. It might be helpful to try to explore one issue and possible explanation at a time. Students change, especially in the first few weeks and months after a life-altering injury. They progress through stages of recovery and of emotional adjustment. These ongoing changes require ongoing reconsideration of the intervention and support plans and ongoing adjustments. Interesting changes in ability profiles and emotional and behavioral profiles can, of course, continue throughout the school years. This process should really become part of educators' thinking about all students. At its core, it is simply systematic problem solving that is relevant to all student problems as they evolve over time at home or at school.



We hope that this website, its problem solving system and the tutorials with their intervention and support suggestions are useful for you. We wish you the best as you serve your students in the most effective manner possible.

On behalf of the Brain Injury Association of New York State, we would like to thank the families, educators, advocates, state and local government agencies, and especially the students who are living with brain injury who have offered their time and energy in helping us to create this comprehensive system of information and support.

We gratefully acknowledge funding support for Project LEARN provided by the Developmental Disabilities Planning Council and The New York State Office of Mental Retardation and Developmental Disabilities.

Publications

- **My Child's Brain Injury**, Brain Injury Association of New York State (2003).
- **Transitions to School: from the Hospital, from the Rehab Facility and from Home Developing an Educational Program to Support the Needs of a Child with A Brain Injury**, Brain Injury Association of New York State (Revised 2008).
- **Traumatic Brain Injury: A Guidebook for Educators**, New York State Education Department (2002).
- **A Guide to Being Heard**, Brain Injury Association of New York State (2003).

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 and vocational resource and advocacy.

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

44 Holland Avenue

Albany, NY 12229

518-473-1890

Web Site: 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 Education Department; Office of Vocational and Educational Services for Individuals with Disabilities (VESID)

New York State Education Department
Vocational and Educational Services for Individuals with Disabilities
Special Education Policy
One Commerce Plaza, Room 1624
Albany, New York 12234
Phone: (518) 473-2878
Email: vesidspe@mail.nysed.gov
Web Site: www.vesid.nysed.gov
VESID provides services and support for students with disabilities.

New York State Department of Health (DOH)

Bureau of Long Term Care
Medicaid Brain Injury Program
Office of Medicaid Management
One Commerce Plaza
Albany, NY 12260
518-474-6580
E-mail: nyhealth@health.state.ny.us
Web Site: www.health.state.ny.us
DOH provides many essential services for individuals with brain injury and administers the Home and Community Based Services TBI Medicaid Waiver.

The Commission on Quality Care and Advocacy for Individuals with a Disability

401 State Street
Schenectady, NY 12305
Telephone: (518) 388-3892
Web Site: <http://www.cqc.state.ny.us/default.htm>

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.



Other Resources:

Resources for Children with Special Needs

116 E. 16th Street 5th Floor, New York, NY 10003

Telephone: (212) 677-4650

Web Site: 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: nichcy@aed.org

Web Site: www.nichcy.org

Parent Advocacy Coalition for Education Rights (PACER Center)

8161 Normandale Blvd., Bloomington, MN 55437

Telephone: 888-248-0822

Fax: 952-838-0199

E-mail: pacer@pacer.org

Web Site: www.pacer.org

Lash and Associates Publishing/Training

708 Young Forest Drive, Wake Forest, N.C. 27587

Telephone: 919-562-0015

Web Site: www.lapublishing.com

National Early Childhood Technical Assistance Services (NECTAS)

517 S Greensboro Street, Carrboro, NC 27510

Telephone: (919) 962-2001

Email: nectac@unc.edu

Website: www.netac.org

(Avner/Weller, 2008)