ACQUIRED BRAIN INJURY NETWORK OF PENNSYLVANIA, INC.
Survivors and Families - Building Lives of Meaning, Joy and Value
2275 Glenview Drive, Lansdale PA 19446 Phone: 215-699-2139
Email: info@abin-pa.org Website: www.abin-pa.org

POSITION PAPER

NEGLECT VS. RECOVERY FOR BRAIN INJURED CHILDREN: Reducing Downstream Costs by Implementing the Federal E.P.S.D.T. Mandate

Through the Head Injury Program in the Department of Health and the CommCare and OBRA Waivers in the Department of Public Welfare, Pennsylvania provides brain injury rehabilitation to about 500 adults out of the 245,000 Pennsylvanians disabled by traumatic brain injury.

In contrast, Pennsylvania does not rehabilitate children after brain injury.

Children experience even greater consequences than similarly injured adults. Their record of achievements to date is less complete and interference with new learning limits their potential. Not only does brain injury compromise further brain maturation, but further brain injuries are more likely and each causes progressively greater damage.

By definition, damage to the brain from traumatic or non-traumatic injuries interferes with the neuronal networks that control everything about our lives.

1. Physical effects: seizures, unsteady balance, spastic muscles, lack of coordination, weakness, paralysis, vision problems, hearing problems, slurred speech, headache, fatigue, loss of smell, loss of taste, etc.
2. Cognitive effects: short/intermediate/longterm memory, processing speed, reaction time, word finding, concentration, judgment, planning, conversation, organization, spatial awareness, starting an activity, completing an activity, multi-tasking, etc.
3. Behavioral effects: anxiety, depression, mood swings, impulsive behavior, easy agitation, egocentric behavior, difficulty accommodating others, inappropriate behavior, etc.

In the face of these devastating changes, parents must advocate for treatment based on periodic neuropsychological evaluations and create a consistent atmosphere of rehabilitation within in the home. The goals of brain injury rehabilitation are:

1. to provide stimulation alternating with rest to encourage the brain to repair itself.
2. to promote understanding and cooperation between the child, family, and others.
3. to re-establish former skills and habits.
4. to embed compensatory strategies.
5. to provide emotional support and encourage hope.

Without rehabilitation, children face these challenges alone. Their schools and families have no way to understand their needs. Depending on the extent of interference with neuronal networks, the physical, cognitive and behavioral changes after brain injury may lead to:

1. Impaired brain maturation limiting age appropriate behavior.
2. Impaired life roles, socialization, family connections.
3. Academic impairment and school failure.

4. Unemployment and/or vocational limitations.
5. Juvenile and criminal justice involvement.
6. Substance abuse involvement.

Brain injury caused by trauma is the most common cause of disability from birth to age 45 according to the Centers for Disease Control and Prevention.

Statistics on the Pennsylvania Department of Health website for 1995-1999 tell us that in 2004 there were over 32,000 children under age 21 with a history of hospital admission for traumatic brain injury. The extremely conservative multiple of 4 gives an additional 128,000 children with a history of emergency room discharge for traumatic brain injury.

To this number must be added the children with non-traumatic brain injury from causes such as a high fever, poisoning, brain infection, cardiac arrest, stroke, near drowning, near suffocation, near freezing, heat stroke, alcohol, drugs, anesthesia, brain tumor, brain surgery, chemotherapy, radiation, and other events.

Despite the gravity of this situation, Pennsylvania has consistently ignored the federal requirement that states receiving Medicaid must provide Medicaid-eligible children under age 21 with "such other necessary health care, diagnostic services, treatment, and other measures described in subsection (a) of this section to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan." 42 U.S.C., Section 1396(d)(r)(5).

Since all disabled children in Pennsylvania are Medicaid-eligible despite parent income, plans are clearly needed to avert downstream costs and funding for irrelevant services. The danger of delinquency is illustrated by a study that found 1 in 5 children, adolescents, and adults were arrested within five years of a brain injury. Recently, inmates in the Minnesota state prison system were screened under a federal grant. Of 1,000 consecutive male admissions to state prison, 200 had a history of one brain injury, and 650 had a history of more than one brain injury. This rate of 85% is unmatched by any other disorder.

Irrelevant services can be avoided by screening children as they come into any publicly funded child-serving system such as

Pennsylvania has failed to comply with the federal E.P.S.D.T. mandate in federal Medicaid law in regard to children needing physical, cognitive and/or behavioral rehabilitation after brain injury.

1. Absence of any plan to identify, screen, evaluate, treat or monitor children with brain injury.
2. Absence of intake or annual screening for children coming into publicly funded services such as Medical Assistance, Early Intervention, Children & Youth, Juvenile Justice, Mental Health, Mental Retardation, Substance Abuse, or Special Education.
3. No Medical Access billing codes for essential neuropsychological evaluations and services in state physical healthcare contracts or county behavioral healthcare contracts, denying children's need for informed treatment planning and consultation on strengths, weaknesses and compensations.
4. No denial letters are provided when parents are told services are not available.
5. Medicaid appeals are impossible due to the lack of denial letters.
6. Special Needs Coordinators in the physical healthcare plans do not organize rehabilitation even when they have coordinated the child's hospitalization for medical care due to the injury.
7. County behavioral health contracts prohibit services to those with a primary diagnosis of brain injury as different care is required - but there is no alternative.

Pennsylvania's parents receive misinformation. This misinformation causes them to overlook their children's need for support and guidance from brain injury professionals through the long course of rehabilitation and recovery.

1. Hospitals and other medical providers mistakenly explain to parents that Medical Access does not provide brain injury rehabilitation to children when this is a federal entitlement and there should be denial letters which would provide for appeals.
2. Hospitals and other medical providers are unaware of the rehabilitation programs that the state is funding for adults with brain injury through the Department of Public Welfare's CommCare and OBRA Waivers and the Department of Health's and the requirement that children receive necessary services whether or not they are on the state Medicaid menu.
3. Hospitals and other medical providers mistakenly explain to the parents that the school will take care of the child's needs; however, schools have no authority and accept no obligation to identify, evaluate, collaborate with other professionals, follow any external neuropsychological evaluations, or rehabilitate a child with a brain injury.

How should child-serving systems maximize recovery? What would allow state funds to be spent on services which truly bring help to children struggling with the aftermath of brain injury?

1. Use one comprehensive protocol and standardized treatment standards for all systems.
2. Require brain injury training for Special Needs Coordinators, staff and licensed professionals who will serve or impact services to the child with brain injury.
3. Order neuropsychological evaluations and help parents appeal rejections.
4. Promote a 24/7 therapeutic milieau with everyone on the same page.
5. Require all to promote recovery by following the guidance of the child's neuropsychologist.
6. Stop delays due to impasse between schools, Medical Assistance, and third party payors.
7. Set a thirty day response time to force decisions.
8. Do not place children with brain injury in behavioral health, mental retardation, substance abuse or juvenile justice programs without a neuropsychological evaluation and treatment plan based on those recommendations.
9. Implement a transition process from child serving systems into adult serving systems to ensure consistent and comprehensive services for consumers with brain injury.
10. Incorporate a standard, comprehensive, best practices module for brain injury rehabilitation into every child-serving system and assure ongoing staff training and annual refinement of the module.

SUMMARY: Children require and are federally entitled to rehabilitation
Regardless of current or past history, contractual barriers, lack of denial letters, lack of appeals, or best intentions, Pennsylvania is federally mandated to comply with E.P.S.D.T. §1396(d)(r)(5) and provide rehabilitation to all Medicaid-eligible children under age 21 who are disabled by brain injury.

Politically silent children are waiting to recover their lives.

Questions and comments are welcome.