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ACQUIRED BRAIN INJURY NETWORK OF PENNSYLVANIA, INC.

Survivors and Families - Building Lives of Meaning, Joy and Value

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POSITION PAPER – 2008.11.20

**Best Practices: Serving Traumatic Brain Injury Survivors
Within Trauma Informed Mental Health Systems of Care**

A national movement within the mental (behavioral) health system now screens for and addresses psychological trauma from physically and/or emotionally traumatic events.

The United States Department of Health and Human Services' Substance Abuse and Mental Health Administration at www.samhsa.gov now provides 1,090 links to "trauma informed care" including a link to <http://mentalhealth.samhsa.gov/nctic/trauma.asp>, the National Center for Trauma-Informed Care at 1-866-254-4819 or nctic@nasmhpd.org.

Screening for traumatic events is especially important for populations who are known to have high rates of brain injury including those who are victims of domestic violence (67%), batterers (100%), returning from Iraq (33%), seeking mental health services (58%), affected by mental retardation (75-95%), or incarcerated (80%).

Trauma informed care at its best will incorporate best practices in brain injury rehabilitation including identification, neuropsychological evaluations, assessment for sensory and physical impairments, rehabilitation treatment planning, and rehabilitation services, including cognitive rehabilitation therapy. These practices harness the ability of the brain to re-learn, repair and compensate.

Thorough evaluations are essential for treatment planning and will differentiate those with brain injury from those affected solely by emotional trauma. Some of the common cognitive effects of brain injury involve memory, judgment, attention, decision-making, visual comprehension and auditory processing. Brain development is often affected. Behavioral effects often involve impulsivity, easy irritability, anxiety, mood swings, egocentric behavior, violence, and depression. Catastrophic stress reactions occur when cognitive or sensory processing systems are overwhelmed. Sensory problems often involve vision (tracking, accommodation, blindness, one sided neglect), hearing (background/foreground, deafness), smell, taste, and sensitivity to light, noise or motion. Finally, some common physical problems involve balance, gait, swallowing, paralysis, spasticity, coordination, and seizures.

Now that the importance of trauma has been recognized, best practices in mental health can be combined with best practices in brain injury rehabilitation to make the best use of time, human potential, and scarce resources in promoting recovery.

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November 5, 2010

Shaye Erhard
Office of Mental Health and Substance Abuse Services
233 Beechmont Building, DGS Complex
P. O. Box 2675
Harrisburg PA 17105-2675

RE: Comments on Regulation No. 14-522

Dear S. Erhard,

ABIN-PA is sending comments on this Regulation for Residential Treatment Facilities serving children under age 21 to urge OMHSAS to provide appropriate services for the children with brain injury in these facilities.

Several studies indicate that a history of brain injury is more common in children and adults with behavior requiring special attention than the prevalence of about 8.5% in the general population.

- When the Mt. Sinai Brain Injury Screening Questionnaire was used to assess children in the City of Chicago Special Education system, 20% of those considered learning disabled and 30% of those considered seriously emotionally disturbed were actually brain injured.
- Without brain injury rehabilitation, 1 in 3 adolescents and adults will be arrested within 5 years of a traumatic brain injury.
- On 9/25/2008, the University of Michigan News Service reported that a study of 720 residents age 11-20 in a Missouri rehabilitation facility for delinquent youths found 1 out of 5 or 132 of them had experienced a traumatic brain injury where they were unconscious for at least 20 minutes. These teens had "significantly earlier onset of criminal and substance-using behaviors, more lifetime substance abuse problems and suicidal tendencies than youths without a traumatic brain injury." It is worthwhile noting that the test criteria of unconscious for 30 minutes restricted the test to those with moderate or severe brain injury, but mild brain injury is much more common and can also cause cognitive/behavioral dysfunction.
- The Centers for Disease Control and Prevention page on prisons and brain injury at www.cdc.gov states 25% to 85% of inmates have had one or more brain injuries, depending on the detail of questions asked.
- In Minnesota, a screening of 1,000 consecutive adult male admissions to state prison revealed that 85% had one (200) or more (650) previous brain injuries.

Since RTF's will serve 6,000 youth with a diagnosis of mental illness or serious emotional or behavioral disorders, with or without a drug and alcohol diagnosis, the studies above would indicate that a very large number of these children, perhaps one third, will have had a brain injury. It is extremely important to identify these children and provide them with brain injury rehabilitation for their physical, sensory, cognitive, emotional, and behavioral dysfunction rather than subject them to best practices in mental health care, trauma-informed care, or routine psychiatric prescribing. This is the only way to change the path of their adult lives. This may be their only opportunity since Pennsylvania has no other system for identifying and rehabilitating children with brain injury.

Since the brain controls all of human life, missing connections in the neural networks impact physical, sensory, cognitive, emotional, and behavioral function. Most people with brain injury have a few problems in each of these categories causing challenges in relationships, work, play, school, and the activities of daily life. Physical effects may include: fatigue, weakness, spasticity, flaccidity, paralysis, changes in appetite, balance problems, gait problems, trouble coordinating a sequence of muscle movements as in brushing the teeth, swallowing problems, sphincter control and awareness, slow reaction time. Sensory effects may include: vision disturbances and

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blindness, loss of taste, loss of smell, hearing disturbances and deafness, sensitivity to noise or light, sensitivity to motion, sensitivity to odors. Cognitive effects may involve: memory, concentration, judgment, awareness, decision-making, cause and effect, multi-tasking, confusion, inability to learn new things, loss of academic skills, cognitive overload, loss of job skills, loss of social skills, anosognosia (loss of awareness of the self). Emotional effects may involve: volatile emotions, grief, anger, mood swings, anxiety, depression, rage, apathy. Behavioral effects may involve: perseveration, inability to transition, isolation, egocentrism, ignoring others, standing too close, being intrusive, inability to participate in a conversation or a group discussion, getting lost from restroom to restaurant table, stepping into the street without looking, failing to maintain hygiene, failing to follow a routine, failing to follow rules, misattribution of blame, unable to participate in sports, does not remember he has eaten, eating whenever he sees food, sleeping much more than others, unable to arrange clothing.

Continuing my comments on the introduction:

- To maximize parental involvement, children with brain injury should be placed close to home, or re-located closer to home when space becomes available, because familiar faces and lifetime family involvement are critical to quality of life and recovery.
- Children with brain injury will be helped by the prohibition of prone restraint and the classification of restraint through drugs as a reportable incident.
- The parents of children with a history of brain injury must be protected from harassment when they advocate for brain injury rehabilitation or complain about the deleterious effects of routine mental health care. They must be encouraged to advocate for brain injury rehabilitation instead of accepting behavioral health treatment for their children. To this end, every facility accepting children with a history of any brain injury must have a contracted neuropsychologist, a contracted neuropsychiatrist, and staff with training in brain injury rehabilitation. Having appropriate staff will prevent maltreatment and the inducement of more severe behaviors by imposing inappropriate medication on children who do not have a mental illness.
- Screening and diversion into appropriate facilities are essential to prevent staff without brain injury training from setting goals for children and families dealing with brain injury.

Continuing with comments on the introduction:

- Section 23.183 regarding prescription medications must require that the child and family also be told of the paradoxical impact of some psychiatric and non-psychiatric medications on those with brain injury so that these effects will be reported quickly if observed, and interference with recovery will be minimized by quickly adjusting doses or quickly providing substitute medications. Current experience is that these reactions are considered imaginary or unimportant and there is no urgency to correct medications when untoward reactions or suffering are observed. Instead, doses are increased, further medications are added.
- Section 23.190 should detail the diagnoses of children on multiple psychotropic or any anti-psychotic drugs and indicate the percentage of those on each who have a medical history including one or more traumatic or non-traumatic brain injuries broken down into mild (not unconscious), moderate (unconscious up to a day or so), and severe (unconscious for days to months).
- Section 23.201 – 23.206 should specifically include proactive, preventive, and de-escalation techniques that are appropriate for those with varying levels of dysfunction due to a medical history of brain injury. Section 23.203 should include structured day planning including rest periods to assure a peaceful, satisfying environment for those with brain injury to minimize catastrophic stress reactions.
- 23.221 – 23.230 must include comprehensive physical, sensory, cognitive, emotional, and behavioral evaluations, diagnosis, planning and rehabilitative services for those with brain injury. The brain controls every aspect of our lives through extensive interlocking neural networks. A child with 20/20 vision who cannot process visual input will have unruly behavior. A child with difficulty swallowing, an unsteady gait, or balance issues will be emotional. Many brain injuries occur with a jerking of the head which may cause a subluxation of one or more vertebrae. A child with a subluxation impeding blood flow to the brain will have difficulty paying attention and controlling behavior.
- “Affected Individuals and Organizations” should be expanded to include physicians, psychiatrists, neuropsychologists, neuropsychiatrists, speech & language pathologists, occupational therapists, physical therapists, optometrists providing vision therapy, chiropractors and other professionals who specialize in or

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are comfortable with the needs of children with brain injury in order to properly plan for the physical, sensory, cognitive, emotional, and behavioral needs that may follow brain injury.

Turning to the regulation itself:

Page Cite Comment

011 iii A drug used as a restraint “is not standard treatment for child’s medical or psychiatric condition”. Once there is a brain injury, certain psychiatric and non-psychiatric drugs must be avoided or used with extreme caution. The child’s medical record must be clearly marked so that unsuitable medications are not provided, otherwise chemical restraint may occur accidentally. The prevention of drug reactions caused by a prior brain injury requires attention to both the menu and dosage of both medical and psychiatric drugs.

012 “Emergency safety situation” – those without training in brain injury may react too quickly or too slowly to emerging situations. Many of the harmless behaviors common or typical after brain injury will appear to be unanticipated by those without training and experience with this population.

012 “High Fidelity Wraparound” teams must include brain injury professionals for children with brain injury and the entire team must receive brain injury training if they are to be able to help families. Many behaviors after brain injury do not respond to outside intervention, personal effort, the child’s willpower, or medication, so special training is required.

_____ “Hospital reserved bed day” – to maintain continuity in treatment, a staff member must accompany the child with brain injury or be available daily if the child is sent to another facility. It is very likely that others will have no training in brain injury and if they are unable to interact positively with the child, months of progress could be undone.

_____ “Intimate Sexual Contact” should not specify the presence or absence of clothing. Inappropriate physical contact of an intimate sexual nature does not require the removal of clothing, merely the rearrangement of clothing. By specifying that clothes must have been removed, perpetrators can protect themselves by merely rearranging clothing.

_____ “Trauma-informed Care” – see attached position paper. Where physical trauma has resulted in a brain injury, mental health best practices are not appropriate.

019 (17) A prescription medication error should include attempting to medicate brain damage or brain injury as if it were mental illness.

026 (2)(vii) A child under 18 is a minor and should not be treated as an adult unless the child is also assuming the parent’s responsibility for the care and supervision of the child and the obligation to assure school attendance – which could not happen. For the mental health professional to disturb the balance of power between a minor child and the parent in this way is irresponsible. Anyone who has raised children knows that a 14 to 18 year old has very little ability to evaluate present or future consequences, and would have very little ability to resist the will of residential professionals who control the environment. I have known residential professionals to force an adult to sign papers, and in another case, to convince a child that there was no brain injury despite a hospital report of frontal lobe damage and a 50% drop in IQ. By taking the position that a child beginning at 14 has the right to decision making, the state can manipulate the child because the child cannot leave the facility and may fear repercussions. If the minor cannot legally contract with a third party, how can the state give them adult status for mental health decisions? Mental health professionals told one child in advance of his 14th birthday that on that day, he could decide whether to take his medicine or not – so he stopped, leading to very unfortunate consequences regarding school behavior. This is a crucial issue for children with brain injury as teenagers and young adults want to believe that they are invincible. If the child is not engaged in rehabilitation immediately and throughout the teen years, adult performance will be severely impacted – yet no one could expect the child to understand this

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harsh reality. The signature of a child under age 18 should have no legal meaning and should not be considered proof that the child understands what was signed, particularly if that child has a brain injury. If the state disapproves of the parent, then proceedings to remove the parent should begin, but usurping the power of the parent by interposing the state between the child and parent is not appropriate. There are many stories of children with brain injury who would not cooperate through their teen years, finally realizing that the world was passing them by in their 30's when others have degrees, jobs, cars, vacations and their own families. A child of 14 to 18 has no way of understanding their own situation and the impact of their decisions on the remainder of their lives.

028 Informing a 14 – 18 year old of their legal rights or getting the signature of such a child should have no legal meaning. Either the parent or a court appointed guardian should be the person involved in conversations about rights, not the state dealing with the child – an unequal contest. A child in an RTF cannot be said to be in a position to make independent choices unless they can walk out the door and support themselves.

028 (2) What efforts are legitimate in forcing a child age 14 to 18 to sign a document, and what legal effect could this have with the specter of coercion hanging over the situation, even silently, as the facility is providing food and shelter.

028 (e) What independent person will assist the child or the parent in filing a grievance against the RTF and how will retaliation be prevented – would the child immediately be moved to another facility? A child with a brain injury or under incorrect medication would have no ability to file a complaint. The parent would not understand the need to file a complaint unless the dangers of inappropriate medication and treatment were made known to them.

23.32 (a) Add “medical condition requiring treatment”.

23.32 (d) A child with a brain injury may never grasp the rules, or remember the rules, or know when to apply the rules – what will be the punishment? How will this be handled when a medical condition prevents compliance with the rules? A child with a brain injury would need a neuropsychological evaluation to determine which rules they could be held responsible for following.

030 (l) ...including brain injury rehabilitation for the physical, sensory, cognitive, emotional, and behavioral effects of brain injury. The sensory limits of the child must be known – for example, the child who has lost the sense of smell will not smell the smoke of a fire – and the child who has lost the sense of taste may eat foods that have gone bad.

031 (b) The child with brain injury may still fail to understand the restraint policy. Staff in facilities that accept children with brain injury need training to maximize diversion and minimize the child's frustration, especially when connected to cognitive overload. Some strategies for preventing cognitive overload are the “stop” signal allowing the child to be left alone or go to a private location, self-soothing strategies, rest periods in the schedule, pacing, more intense activities in the morning, etc.

032 (4) For children with brain injury, family services must focus on brain injury best practices.

033 (9)(i)(ii) Family expectations must include family training in brain injury and recovery, caregiver information and support, and information on the child's strengths and weaknesses, best learning modalities, compensatory strategies, and assistive technology to enhance the resilience of the family for long term family focused rehabilitation.

035 _____ The medical director seems responsible for all children in the facility – but how many can really be served properly by one person? Including family contact, staff training and supervision, and written psychiatric evaluations, this appears to be more responsibility than one person can adequately discharge, depending on the size of the facility.

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036 ____ How can the medical director with no training in counseling serve as the clinical director?

042 ____ All staff in facilities accepting children with brain injury must be trained in managing the behaviors of those with brain injury.

045 (e) This section provides special directions for serving children with ASD – there should be another section on facilities serving children with brain injury.

060 (6) Must include a brain injury screening that screens for events that may have cause a traumatic or non-traumatic brain injury and also screens for the aspects of cognitive dysfunction that are known to be common after brain injury.

060 (7) The detection of events involving force (tornado, assault, car accident) must result in a further assessment for the aspects of cognitive dysfunction that are common after brain injury.

061 (8) and to the use of specific medications.

061 (iv) including brain injury.

061 (xii) neuropsychological testing of the functions of the brain and the results.

061 (3) and a brain injury screening test.

065 (16) a chiropractic evaluation and treatment for subluxations compromising spinal and cranial nerves and blood flow to the brain.

065 (17) vision and hearing tests for function and comprehension (in addition to refraction and acuity).

23.148 (b) add neuropsychological, speech and language evaluation, occupational therapy evaluation, physical therapy evaluation, functional vision evaluation, and functional hearing evaluation.

Risks: The child with a brain injury is at increased risk for subsequent events that may cause another brain injury, usually due to slow reaction time and poor judgment. Each subsequent brain injury will cause greater injury than to a person having no prior history. The effects are cumulative. After each injury, brain biochemistry requires three months to return to normal. Re-injury during this period is unwise, so each injury requires a period of protection from further injury to minimize cognitive decline.

074 ____ Very glad to see alternative and complementary strategies included. Chiropractic, hyperbaric oxygen therapy, homeopathy, Polarity, Shiatsu, natural whole foods nutrition, Bach Flower Remedies, herbs, Trager, massage, and acupuncture all bring benefits that are not available through conventional medical care. The goal should be restoring lives.

094 (9) include brain injury.

094 (6) with special note of events that may have caused a brain injury.

097 (b)(1) demonstrating that any trauma-related factors or brain injuries are being addressed in clinical treatment.

097 (3) include neuropsychological (brain function) needs.

097 (c) Team must include a brain injury professional if the child has a history that includes one or more brain injuries.

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098 (2) Treatment team must include a brain injury professional if the child has a medical history that includes one or more brain injuries.

099 (e) parent, guardian or custodian must have the right to bring an advocate.

102 23.227 Age 14-18 is not an age period known for rational decision making. Ask any middle school or high school teacher. At this age, many foolish and dangerous behaviors are enjoyed and planning for the future is not really possible for most. Children who think that they have the power to make mental health decisions are being deceived, because their parents are still responsible for them. It is foolish to instigate a power struggle between parent and child in the name of mental health. The parent should be shown respect by the professional. If the parent is not adequate, steps should be taken to secure a guardian.

103 23.228 (2) As for ASD, behavioral health treatment is not appropriate, but rather is destructive for children whose behavior is due to cognitive dysfunction after brain injury. Evidence based best practices for mental health are not the same as for brain injury. Even where there is a substantial accumulation of data on best practices for mental health, this is not an excuse for applying these practices to a person with a different condition, just because some of the behaviors may appear to be similar. Brain injury is not a mental illness. There used to be fever hospitals when a fever was considered to be a separate disease with specific treatment. Nowadays, we consider the fever to be a symptom of illness, and we look beyond the symptom to treat the cause of the illness such as the flu or pneumonia. Unfortunately, our behavioral health system is also treating a symptom. The unacceptable behavior is considered to be the disease and there is specific treatment for that behavior. It is past time to look beyond the symptom of behavior and treat the cause such as a brain tumor, meningitis, malnutrition, allergies, mental illness or brain injury. One Pennsylvanian was given behavioral health treatment for schizophrenia for 15 years until her brain tumor was removed and she returned to normal.

103 (3) typo – “hope”. Groups are often very difficult for those with brain injury and often counterproductive because there is too much stimulation, the location of the voice cannot be identified, the conversation moves too fast, etc.

103 (4)-(8) Use brain injury best practices.

105 (b) The community behavioral health agency must be capable of continuing brain injury rehabilitation services.

105 (d) Brain injury must be clearly marked in the psychiatric discharge summary and the final evaluation.

107 (2) physical health records, including documentation of any history of brain injury.

108 (5) neuropsychological evaluations and testing.

140 (j) who is paying for healthcare, other than for behavioral health, if not Medicaid?

157 ____ DPW has not yet determined that brain injury rehabilitation is necessary for children, thus it is easier to ignore these children than to treat them.

Thank you for this opportunity to comment. Please contact me with any questions.

Best regards,

Barbara A. Dively
Executive Director

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