

Traumatic Brain Injury: Looking Back, Looking Forward

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The following article is the eighth of a multi-part series on traumatic brain injury (TBI).

Historically, TBI has received limited national attention and support. However, since it is the signature injury of the military conflicts in Iraq and Afghanistan, TBI has gained attention of elected officials, military leaders, policymakers, and the public.

This series is published by the Traumatic Brain Injury—Resource Optimization Center (TBI – ROC) and its Advisory Group, facilitated by JBS International, Inc. The TBI–ROC is a recognized source and leader for advancing national attention to the myriad of policy, research, practice, and service needs supporting of civilians and military individuals who incur TBI and their families.

The past seven *Exceptional Parent* articles have discussed and explained the medical aspects and daily life challenges faced by a child, teenager, and young adult who incurs a TBI and the impact on the family. They explain the differences between mild, moderate and severe TBI. The continuum of rehabilitation (inpatient, community integration, & lifetime of care) is explained and how an individual proceeds through each stage to obtain his/her highest level of functioning. The articles review the different types of rehabilitation interventions and the important role of caregiving, the importance of immediate screening, as the earlier a TBI is identified the sooner a course of treatment and rehabilitation can be identified and begin. The importance of assessment and reassessment is key to ensure treatment matches the individual's changes in functioning, as no individual with a TBI is the same. The problem that many families face is a fragmented, complex rehabilitation service system and confusing health insurance coverage. Depending on functioning, a child with TBI may be eligible for special education and other related services (as supported by the Federal Individual with Disabilities Education Act (IDEA). The articles discuss employment and how it is increasingly more difficult for younger individuals. The importance of the family is emphasized. Family dynamics can affect rehabilitation outcomes. Assistive technology devices (ATDs) are helpful in providing support to an individual's recovery. Unlike paper methods, ATDs can remind a person of appointments and other events. Unique tools such as the use of a camera can be helpful in enhancing the rehabilitation process.

This eighth, two part article, will tell the story of a nationally recognized TBI advocate, including information on understand-

ing public and private health insurance, and an ATD creative initiative. This article and its follow up support the family and the child with a TBI becoming a full member of the TBI advocacy community, and attaining a full community life.

Theresa Rankin's Story

It has been 41 years since the car crash that changed Theresa Rankin's life. Theresa has continued to battle back from TBI and pursue her goals despite her difficult journey. She is a model for teenagers and young adults who incur a TBI and their parents and siblings.

At 21, Theresa was a junior at San Diego State University majoring in social science and environmental studies. She enjoyed the rigors of the coursework and was excelling in her studies. In 1977, Theresa temporarily ended up in a coma after the car she was riding in careened off a cliff. Theresa was diagnosed with a brain injury to her frontal lobe. Doctors diagnosed her with moderate brain damage, and sent her to live with her parents, cautioning she might experience memory problems. What Theresa ended up enduring was more debilitating than forgetfulness. Eating, coping with loud noises, reading and chronic fatigue were all challenges.

In 1985 doctors correctly diagnosed a brain injury. She was placed into a rehabilitation program. While the program provided benefits, Theresa felt the need to "escape" because it was geared toward placing her in jobs that did not require high levels of training. Rather than reintroducing her to the science she once excelled at, she was coaxed into careers such as a file clerk. Theresa returned to college in the late 1980's and completed her

schooling. She became a community relations consultant.

Her social work and efforts to learn more about TBI led her to travel across the country. An important connection was made with WETA (a public radio station) in Washington, D.C. The public broadcaster forged a partnership with her BrainLine project. Her life's work as a national community educator led to establishing BrainLine.org, an Internet-based resource that took 13 years by pulling together a team of support, through Theresa's effective and compelling advocacy.

Theresa has constantly struggled but never lost her dream. "Her goal is to ensure that understanding TBI is publicly understood and to reach out to the millions of people all who have survived a brain injury but don't know where to turn." In addition to checking out the web site at www.brainline.org, Theresa encourages the public to get answers on TBI questions by emailing "Ask The Expert" at info@brainline.org.

Special Education. This information is based on a case manager's experience with individuals with TBI. This case manager has helped individuals access services and navigate complex health care systems and the confusing array of funding sources.

Private Health Insurance

Group Health Plans: These are the health plans employees annually enroll. The largest plans include Anthem, Blue Cross Blue Shield, Cigna, and United Health Care. As health care costs have increased, premiums have increased and many plans have restricted benefits to manage costs. It is important to obtain a copy of explicit benefits to know what is and not covered. Group health plans often apply the concept of "medical necessity" to determine whether a covered individual is entitled to receive a particular therapy. Many times medical necessity is decided on the basis of basic functioning such as being able to bathe, dress, or eat independently. If someone is independent in these areas, some plans limit access to



Understanding Private and Public Health Insurance

Theresa was initially supported by her father's enrollment in CHAMPUS, now called TRICARE, as a dependent. CHAMPUS did not provide care coordination and her parents could limitedly help her when CHAMPUS coverage ended. She remained in San Diego without health insurance, trying to re-integrate into employment and academic studies. She was homeless and unemployed for at least 9 years. Theresa did not obtain Medicaid and SSI (Social Security Income) supports until 1988 after finding her way to Virginia and connecting with a rehabilitation center and the James and Sarah Brady's advocacy for survivors with a TBI. She has received access to mental health, TBI rehabilitation and cranio-facial reconstruction but remained homeless until November 1992.

For those with a TBI and their families, one of the greatest challenges is accessing funding for rehabilitation care that will allow recovery. There is limited understanding of insurance limitations and complexity. TBI care is typically fragmented with many "funding streams" for rehabilitation, often based on the individual's injury and age. Many have no coverage or limited coverage. Insurance coverage rarely follows an individual throughout the entire rehabilitation continuum. Even dependents that are listed on both parents' group health plans and have access to auto insurance due to a motor vehicle accident, can end up needing state Medicaid for support within 12 months of injury.

The following insurance information includes specific information on private, public and military health insurance and

allied health therapies (physical occupational and speech therapy) as not medically necessary. Group Health Plans manage costs by offering plans with higher deductibles in order to offer more affordable premiums. If family members have covered dependents in a "family plan", the member may be responsible for a specified funding level in health care expenses before the insurance begins paying. Group Health Plans offer a network of "preferred providers" that they cover at 100% and non-network providers that may be covered at 70% or 80%, with the member being responsible for the co-payment. It is important to research the quality of the in-network providers before agreeing to the plan. Another form of Group Health Plan is the Health Maintenance Organization (HMO), such as the Kaiser Permanente Plan. An HMO typically has its own hospitals and primary care physicians. It is more expensive to access external providers if covered by a HMO. Health Savings Accounts may be offered as a stand-alone health insurance option or in combination with other traditional Group Health Plans. The Health Savings Account is a pre-tax fund that is established as a payroll deduction that goes directly into a bank account to be used for health care expenses. The member has a debit card that can be used at pharmacies, and with physicians and rehabilitation providers.

Auto Insurance: Individuals living in the state of Michigan and if injured in an automobile accident, the state's Auto No-Fault Insurance law covers all medical and rehabilitation expenses. It is important for those residing in a state other than

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Michigan, to check if the state has a “no fault auto insurance” law to know how medical care and what portion of rehabilitation is paid by the auto insurer. Often, in an auto accident, the auto insurance will be primary and when it is exhausted, billing goes to the next plan available; usually a Group Health Plan.

When employees are injured on the job, they must file a “first report of injury” which initiates a claim. Each state establishes its own rules for Workers Compensation. Workers Compensation pays employees a portion of wages during the time they are out of work and also pays medical expenses related to the injury. In the case of a TBI, Worker’s Compensation may cover all medical treatment, therapies, medications. The injured employee is entitled to continuing medical coverage until reaching what is determined to be “maximum medical improvement.” At that time, the employee’s percentage of permanent impairment is determined. If the percentage exceeds a certain percentage (state specific), the employee is entitled to ongoing wage replacement and medical care until return to work is deemed medically supported including placement in alternative employment positions. Some Workers Compensation insurers offer settlements to injured employees to end ongoing financial responsibility. For catastrophic claims, Workers Compensation insurers frequently assign a case manager whose knowledge of rehabilitation providers who know how to navigate the system of care can help achieve positive outcomes.

Active Duty Military Service Members and Dependents:

Service members and their families, have TRICARE coverage for their health care needs. For active duty service members, care is provided on military bases. Family members/ dependents can access care on installations or may be allowed to seek services in the private sector.

When an individual is transitioned to Veteran’s status, the Veteran’s Administration (VA) is responsible for care. Most states have VA hospitals and outpatient clinical treatment settings. Occasionally approval is granted for a Veteran with a TBI to access private providers for unique care/rehabilitation needs.

Public Funding

Medicaid: Each state establishes guidelines for Medicaid, a program for eligible individuals and families with low incomes and resources. It is a means tested program jointly funded by the state and federal government, and managed by the states. Examples of individuals served are low-income adults, and their children, and people with certain disabilities. Poverty alone does not necessarily qualify an individual for Medicaid. Individuals must meet financial criteria to qualify (annual income maximum) and usually cannot have assets over \$2,500.00 not including home and automobile. When a child has a TBI or other medical condition resulting in chronic medical care needs, the families may apply for ‘Katie Beckett’ funds. This is a special version of Medicaid that does not have income eligibility requirements. Medicaid is the payor of last resort, so any private insurance plan is primary over Medicaid coverage.

Medicaid Waivers: Some states established Medicaid Waiver plans for individuals who sustain a TBI. These Waiver plans are based on an individual’s needs. In discussing Waiver funding, it is commonly said that, “the money follows the person.” This means that an individual’s annual Medicaid budget may include the array of medical/rehabilitation services required—that is, creation of a person-specific annual Medicaid budget to provide for a service plan that could include case management, assistance in the home, special transportation, participation in a day program. Some states have limited numbers of Waiver slots for individuals with TBI. Some states have different kinds of Waivers and some are beginning to offer “Global Waivers” to eliminate the silos of disability-specific funds.

Medicare: provides health insurance coverage to people who are aged 65 and over, or who meet other special criteria (e.g., long-term disability). Medicare operates similar to a single-payer health insurance, but its coverage only extends to 80% of any given medical cost, the remaining 20% must be paid by other means, such as privately-held supplemental insurance, or by the individual. Within 24 months following a TBI resulting in permanent disability, an individual becomes eligible for Medicare. Medicare has different parts, Medicare A, B, C, D. Each part is a different benefit. They provide payment for physicians, hospitalization, medication and therapy. Treatment must meet medical necessity guidelines and an individual must continue to demonstrate progress. The length of therapy under Medicare is generally less than two months.

Special Education: Following a TBI of a school-aged person, it is very important that the parent/guardian sign release forms so that the Director of Special Education in the child’s school receives copies of the medical records. This informs the district that the child can be identified as a special needs student and be evaluated for an Individual Education Plan. Once this occurs, assessments by neuropsychologists, and occupational, physical, speech, behavior therapist may establish a need for supports in the classroom and therapy provided by the school district to facilitate the child’s attainment of educational goals. For many children who have TBI, their school district is the primary funding source for specialized care and services. Students are eligible for Special Education funded rehabilitation until their 22nd birthday.

In 2010, Health Care Reform legislation, “Patient Protection and Affordable Care Act,” was passed into law. This law increased health care benefits for some individuals including: 1). Dependents up to age 26 are eligible for coverage as long as the parent’s health plan includes dependent coverage; 2). Employees and dependents under age 19 cannot be denied coverage because of a preexisting medical condition; 3). For health plans effective on or after September, 23, 2010, certain preventive services must be covered without charging a deductible, copayment or coinsurance when provided by a network provider; 4). For health plans effective on or after September 23, 2010, there will be no lifetime or annual dollar limits on health benefits. For more information, visit www.healthcare.gov to help understand the law. •