

THE

Challenge!

Brain Injury Association of America

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OUTCOMES: WHERE THE RUBBER MEETS THE ROAD

WHAT IS IT ABOUT BRAIN INJURY?

By Susan Connors, Brain Injury Association of America

A recent conversation with an important national journalist sounded like this:

“Susan, What is it about brain injury? Why has there been so little research in your field?”

“Brain injury is a misdiagnosed, misunderstood, under-funded public health problem,” I mimic the standard line from BIAA’s literature.

“Yeah, but why?” he presses.

With input from colleagues and friends, this editorial offers opinions on the challenges in brain injury research, treatment, awareness and advocacy. It doesn’t fully answer the question, “What is it about brain injury?” but it is a start. Readers are welcome to send comments to publications@biausa.org.

Challenge No. 1 – Dealing with the Diversity

No two brains are alike so no two brain injuries are alike.

Brain injury can happen to anyone at any time regardless of age, race, gender, or economic status. The cause, focal point(s), injury severity and resulting symptoms and impairments are heterogeneous, a fancy word that means different.

The diversity in brain injury makes it unlike other medical diagnoses. It also leads to misdiagnosis, or “hidden TBI.” And it makes research harder and more complicated, what experts call “dirty.”

Our language is inconsistent. Cancer is cancer. Yes, there’s breast cancer, prostate cancer, leukemia and others, but the public knows it as cancer. It goes by one name.

Traumatic brain injury is called head injury, head trauma, concussion, TBI, mild TBI, disorder of consciousness, blast brain injury and shaken baby syndrome—just to name a few. If you include the broader classification of acquired brain injury, such as strokes, many, many more terms are used. Wouldn’t it be easier if everyone just called it brain injury?

Different labels are used for the same intervention. To some, it is cognitive rehabilitation; to others it is speech therapy. Conversely, the scope and intensity of a treatment varies from place to place. Rehabilitation in the hospital is not the same as rehabilitation in a nursing home.

Individuals with brain injury are called patients, clients, program participants, survivors, thrivers, experiencing persons and other euphemisms. Just the other day a mom introduced her son by saying, “This is John. He’s a TBI.” Have you ever heard someone say, “This is Betty. She’s a MS” (for multiple sclerosis)?

Public policies, funding and services vary by state, and even the lead agency responsible for brain injury program administration differs from state to state.

Almost nothing in brain injury is homogeneous, a fancy way to say similar.

Challenge No. 2 – Recognizing Brain Injury as a Disease

After all these years, many of us are just now conceptualizing brain injury as a disease, disease-causative and disease-accelerative. That means there’s a cure. How will we find it if no one is looking? There’s an underlying expectation that brain injury will surreptitiously benefit from other neurological research.

In the past, brain injury science focused on neuroprotection, which involves prevention of brain cell death. Today, there is greater emphasis on neuroplasticity, which involves re-wiring the brain’s networks so that functional abilities move from one area to another. It is not as easy as it sounds.

When we think about a cure, we think at a very macro level, such as return to work and independent living. But medications and treatments act on cells and neural networks. There are no “employment” or “independence” networks in the brain. The link between what a drug does and the impact it has on real functioning is shaky.

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Moreover, the links vary from person to person. One person can't work because of behavior problems, another because of loss of balance, and another because of memory problems. Finding a single treatment that would be "effective" in returning everyone to work is nearly impossible.

Even if we could cure an injured brain, it is extremely unlikely that we could restore all the knowledge and skills that it contained before the injury, at least not without extensive re-learning. That brings us to rehabilitation research.

Each physical, cognitive, psychological and social effect of brain injury represents its own set of confounding variables that are difficult to isolate and quantify in a research context. The models that are used for other diseases do not work well for brain injury. The best ones are more like the models used in psychotherapy research, but these are not well known in the medical community. They are hard to control and expensive because they require many study participants.

Funders negatively view much of the brain injury rehabilitation research (both accomplished and proposed) as "soft science." We are caught between two standards: that of rigorous design and that which is clinically and socially relevant, a challenge we are only just beginning to fully appreciate and try to address.

In the meantime, Americans remain a nation of "fixers." If we can't fix the brain quickly, we'll find a "work around." For that reason, and because many insurance companies press for an early discharge, rehabilitation plans quickly shift from restoring lost function to compensating and accommodating for missing skills. It is easier and cheaper to give someone a wheel chair than to teach him to walk again.

Challenge No. 3 – Overcoming Public Depictions and Perceptions

Remember the Looney Tunes characters, Road Runner and Wile E. Coyote? Those old cartoons suggested we can get "bonked" on the head and keep on going as if our skulls, and therefore our brains, are impenetrable.

Most people are not afraid of brain injury. In fact, most people don't think about brain injury at all. Even when

there's been one brain injury in the family, no one expects another.

Hollywood and the news media are doing a better job of portraying and reporting brain injury, but there's still a tendency to present brain injury as a discrete event and something that won't happen to you. Every day it is reported as a car crash, a roofer falling from the ladder, or a young man beaten at a bar. Brain injury is seldom aggregated and explained as a public health epidemic.

Overcoming years of misinformation is an enormous challenge, and yet, it is a necessary first step in helping the public to understand the causes, consequences and magnitude of brain injury.

Americans value intellect. The very idea of a damaged brain is hard to conceptualize, talk about and accept. Some people view brain injury in the same light as mental illness, symbolizing a weakness of character as opposed to a weakness of neural networks. Others think you did it to yourself by not wearing a seat belt or bike helmet.



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Even within the disability community, cognitive impairments are at the bottom of the food chain. Individuals with brain injury are left behind in the shift from an industrial age to a “knowledge-worker” age. They feel the negative effects of globalization first.

There’s very little about brain injury that is glamorous. It is stigmatizing and isolating. Individuals with severe brain injuries disappear from society’s view. They are unable to “tell their story.” This is true even for people who sustain so-called “mild” injuries.

For better or worse, many individuals with brain injury simply don’t look impaired enough to be taken seriously. Until recently, very few athletes or celebrities were willing to discuss their brain injuries publicly. Every day, I quietly thank Bob and Lee Woodruff for changing that.

Challenge No. 4 – Adjusting our Attitudes in Advocacy

Brain injury is acquired. Individuals and families are overwhelmed by the injury so there’s little time, energy or money left for advocacy. The assertiveness that is admired in other disability populations is dismissed as impaired judgment or behavioral disorders in brain injury.

The most common secondary conditions associated with brain injury—depression and substance abuse—further undermine advocacy. And those most likely to be injured, young men, constitute a group whose role in society is not yet fully established. The perceived lack of “personal power” is rampant in brain injury.

Brain injury is a relatively young disability. Advocacy for people who are blind began in the 1800s. As early as 1910, there was a Society for the Feeble-Minded (what later became known as mental retardation and now is called developmental disability.) Thus, brain injury advocacy is nearly 100 years behind its counterparts.

Plus, the disability community is fragmented; each disability vies for its piece of the public funding pie. Until recently, brain injury advocates were not invited to the table.

The ballooning numbers of individuals surviving brain injury starting in the late 1970s and early 1980s coincided with a downward trend in the development of new

services—a “push back” on the entitlement programs of the Great Society. State and federal governments cried, “No Mas!” Today, public safety nets are broken, both in terms of efficacy and cash. In some states, advocates have resorted to legal action.

Meanwhile, the brain injury community is fragmented too. We have multiple, competing agendas within and across prevention, research, services and education. There’s also a lack of cohesion and coordination within and between federal, state and local levels. Given how much time we spend talking to ourselves, our failure to speak with one voice is inexplicable.

Research and treatment are expensive. Awareness is too. These things take money and there’s just not a lot of it in brain injury.

Brain injury leaves individuals and families emotionally and financially devastated. Managed care, downsized employer health plans, and today’s reimbursement policies cut deeply into the pockets of the rehabilitation and long-term care providers. Not much is left to support advocacy. And yet, without the advocacy, federal and state governments will never be forced to invest in basic or translational research.

If we are serious about creating a better future, and I believe we are, we must come together. We may never overcome the heterogeneity of brain injury, but the way we think about and talk about the injury, and thus the perceptions of policymakers, opinion leaders and the public, are changeable.

Many “thought leaders” contributed ideas, full sentences and, in some cases, whole paragraphs to this editorial. I am grateful to the people listed below as well as BIAA’s staff, but I acknowledge that the statement reflects my opinions, not necessarily theirs:

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