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# Brain Injury Advocates: The Emergence of the People with Acquired Brain Injury Human and Civil Rights Movement

*Susan C Hultberg*

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**Brain Injury Advocates: The Emergence of the People with Acquired Brain Injury Human and Civil Rights Movement** Susan C Hultberg

In this groundbreaking book, tbi survivor advocate Sue Hultberg explores the lives, struggles, and issues of people with traumatic and other acquired brain injuries. She examines the origins of the acquired brain injury human and civil rights movement, and she presents an analysis of the key policy and priority agenda for people with brain injuries. She describes how individuals with brain injuries set out to engage in independent policy advocacy at the all-survivor Brain Injury Network. She also singles out some of the advocacy-related work of several dozen other brain injury survivors who work, write, or volunteer in and for the brain injury survivor community. The author draws on her own personal, twenty-five-year-plus, post-tbi journey. She recounts her transformation from accident victim, to traumatic brain injury (tbi) survivor, to community policy advocate, and she expands on what it takes to be a good brain injury survivor advocate (SABI).

The author explains why patients with brain injuries need the medical community to emphasize a post traumatic brain injury syndrome brain injury classification. She also argues that children should never play tackle football or other contact sports (such as boxing) because the risk of sustaining concussions or other brain injury is just too great. She discusses the poverty, harassment, lack of needed services, and stigma that individuals in the brain injury community encounter. She asserts that such terms as brain damaged, brain injury victim, and persistent vegetative state are politically incorrect. She shares policies that could improve quality of life for people with brain injuries who live in nursing homes or other assisted living facilities. She also outlines a selection of protective laws that could shield society from brain injuries.

The author details how important privacy protections for people with brain injuries are undermined by the U.S. government, online social communities, and some medical and other professionals. She also elaborates on how the apparent confusion in concussion (mild traumatic brain injury) and postconcussion definitions, diagnosis, and treatment are making life more difficult for many individuals with brain injuries.

The book caps off with an exploration of the various fundamental human rights that individuals with cognitive, physical, and other disabilities from brain injuries have, including the rights to privacy, safety, happiness, liberty, and up-to-date and adequate medical care. This well-researched book by a TBI survivor author who has professional and scholarly credentials contains an appendix listing books and other materials by individuals with brain injuries. There is also a cross-referenced index.

This book is about people with acquired brain injuries from aneurysm, anoxic or hypoxic injury, illness, stroke, toxin, trauma, or tumor. It is intended for survivors of brain injuries who have turned the corner in their recovery and who want to pay back by helping our community. It is also a must-read book for every advocate, family caregiver, policy maker, professional, program manager, service provider, system administrator, or other brain injury, third-party stakeholder.

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