WRITTEN STATEMENT TO THE CALIFORNIA SENATE HEALTH COMMITTEE

STATEMENT OF SUE HULTBERG

HEARING ENTITLED:

NEW APPROACHES IN THE CARE AND TREATMENT
OF PERSONS WITH BRAIN INJURY

PRESENTED 1-13-10

Not everyone is able to travel to meetings. Please understand the limitations some people with brain injuries have in their function level. This does not mean that every person with a brain injury is intellectually incompetent or needs a service provider to speak for him or her. Some of us are mentally competent, even rather so, and we are able to express our concerns ourselves. But we may be dealing with other issues, for example, physical issues due to some past brain injury, that make it difficult for us to maneuver or to attend or participate in hearings. Some individuals who have experienced brain injury are not up to the task of coming to Sacramento and making public comment in person. We look forward to the day when our government in Sacramento will utilize video communication via SKYPE or similar means in order that we may provide our "public comment" face-to-face. So having said that please note these remarks.

Introduction.

On behalf of the Brain Injury Network we are pleased to submit the following written statement on the committee's important hearing on the issue of brain injury. Thank you to the members of the committee for holding the hearing. Thank you also for calling attention to the issue of brain injury in California. From our side of it, it is not so much the "issue of brain injury" but the "issues of people with brain injuries" that we feel need airing, and so please accept our interjection of commentary regarding our situation into the proceedings. (http://braininjurynetwork.org/publicpolicy/survivorpriorities.html)

Overview.

The Brain Injury Network (BIN) is an all brain injury survivor advocate nonprofit organization that operates from Santa Rosa, California. We have organized and are doing collective advocacy for our community. We would like the California Senate to be aware of our concerns. We have operated for over ten years and held hundreds of meetings in Santa Rosa, California.

We have formulated public policy for our brain injury community which is enunciated on our web site at http://www.braininjurynetwork.org and we invite our representatives in the California legislature to review our policies and to implement governmental policies that promote our ideas. For us it is not merely about medical research or medical care and treatment, or cognitive training. It is about the struggle of our day-to-day lives subsequent to sustaining a brain injury. Our issues are not just cognitive in nature, but also physical, emotional, behavioral, financial, and legal.

Recent studies show the long term or even life-long struggles that we face. There are the cognitive (memory, judgment, communicative, etc.) issues to be sure, but there are other consequences as well. For example, a Mt. Sinai Hospital study stated that individuals with brain injury often face physical consequences such as balance difficulties, sleep disturbances, frequent headaches, seizures, spasticity and loss of urinary control, body temperature changes, and arthritic conditions. Please see the Mt. Sinai web site at http://www.mssm.edu/tbicentral/resources/publications/tbi_consumer_reports_issue1.shtm.

Other studies show hormonal problems, fatigue, somatosensory and perceptual motor issues affecting us. There may also be the possibility of early onset Alzheimer's disease or Parkinson's disease due to traumatic brain injury. Please see the National Institutes of Health web site at http://www.ninds.nih.gov/disorders/tbi/detail_tbi.htm#136333218.

It has been shown that people with brain injuries are more likely to sustain subsequent brain injuries, for example, due to slips and falls, because of their already compromised balance system. We must negotiate life in a careful manner in order to maintain the level of function that we have worked to regain. Please see the Centers for Disease Control booklet at http://www.cdc.gov/NCIPC/tbi/tbibook.pdf.

Because of these medical findings, of late we survivors at the Brain Injury Network are urging that the medical community adopt a traumatic brain injury classification "Post Traumatic Brain Injury Syndrome". Please see our suggestion to the medical community regarding this at http://braininjurynetwork.org/thesurvivorsviewpoint/posttbisyndrome.html.

We at BIN are also seeking the consistent application of the terms TBI (traumatic brain injury) and ABI (acquired brain injury), a broader term which encompasses more than TBI. Other issues that concern us include advocate competency, privacy concerns on social networking sites online, patient data harvesting, provider conflicts-of-interest, helmet laws, "sucker" cures, and patient empowerment. (http://braininjurynetwork.org/publicpolicyindex.html)

The Basic Human Safety Net is the Most Important Consideration.

Our membership has stated repeatedly that our main concern is the basic human safety net. This means basic shelter, food, and medical care. It is our position that the basic human safety net for a person with incapacitating cognitive and/or physical disabilities is even more important than community reintegrative retraining programming. Or, if retraining is funded, it ought to be in conjunction with attention to the participant's basic human safety net. No one can effectively participate in "cognitive training" or other medical programs unless his or her basic human needs have been met. We wish to go so far as to say that if a service provider, hospital, government or other entity wishes to offer community reintegrative or other “cognitive retraining” programming to survivors, it should be part of the program dictate that the provider has seen to it that the participant’s basic needs are being met (housing, food, medical care, etc.), because in these situations one has to assume that the person with the brain injury often doesn’t have the capacity to ensure his or her own safety and basic needs are met.

The types of supports that help survivors function in life and live a dignified life include basic benefits, Medi-Cal or other health programs, food stamps, assisted living, peer support, interventions by social workers, and vocational retraining programs. It is unfortunate that the basic human safety net is under siege here in California due to all of the budget constraints and cuts. For example, underfunding Medi-Cal reimbursements to doctors is putting fragile, vulnerable survivors at risk.

Regarding people with brain injuries who are on Medi-Cal, please understand that survivors have great difficulty finding adequate medical treatment, especially in outlying areas where doctors, especially neurologists, will not see us. Many people with brain injuries in Santa Rosa, California must travel to San Francisco. Yes, survivors on Medi-Cal will be seen for emergencies in local hospitals and by local neurologists at the hospital if it is an emergency situation. But for long-term maintenance of medical issues, such as ongoing medication and treatment for seizures, update imaging scans, neuropsychological evaluations, etc. survivors often must travel so far. Many can’t. Low income people with brain injuries may go to a local “free clinic” but the free clinics don’t have neurology specialists. We survivors might be enrolled in a county managed care health program, but again, the types of specialists we might need do not appear to participate in these kinds of “low income” programs (at least in Sonoma county, California). Again, hopefully this situation will improve with the health care reform being contemplated in Washington, DC.

Medical Treatments and Programming.

There is a heavy emphasis on medical treatments and interventions. One can only imagine how much better life will be for individuals now sustaining brain injuries if they receive the state-of-the-art treatments. It will be better than it has been for the earlier generations of persons who endured brain injuries and who are out in society now. Hopefully some of these newer treatments will offer hope and improvement for the “old timers” as well.

Also regarding the medical advances, we are happy that there is a lot of medical research going on and that there are many new treatments available. Hopefully the many financially destitute persons with brain injuries who currently do not get the health care that they need are able to tap into the newer treatments. We hope the changes coming will help us survivors even here in cash-strapped California.

California.

There are literally tens of thousands of people in California who have experienced some kind of a brain injury and who live with its consequences. Our community members have sustained a brain injury from traumatic brain injury (TBI), stroke, brain tumor, brain illness (example: Meningitis), anoxic/hypoxic brain injury and other causes. At BIN some of our members had a brain injury 5, 10, 20, 30 or even 40 years ago. More and more people live following a severe brain injury due to the advances in medicine in the last several decades. There are also many servicemen and women who returned from prior conflicts or are returning from current war zones who have sustained brain injuries. So, the number of people in this state with brain injuries is rising.

Programs and Community Supports.

One of the biggest problems for people with brain injuries here in California is to negotiate and make use of what community supports and programs that there are. Briefly, even though there are some federal, state, county, city, hospital, private, non-profit and other programs for various aspects of our situation, many fragile, incapacitated people are not still getting the comprehensive help that they need. They fall through the cracks, they flounder, they isolate, or worse, they end living under a bridge or dead. This situation is especially true for survivors who are alone or come from families without much education or means. So goes the life struggle for people with the serious brain injuries in their "post tbi" period, which may last decades. And we know that there is a limit to how much society it willing to help us. However, there are some program supports available here and there. Regarding the attempts by State of California agencies to deliver services to us, we do have a few suggestions for improvement.

Recommendations for California State Level Programming for Californians with Brain Injuries.

Here are a few suggestions.

1. Instruct the **California Community Colleges Chancellor's Office** to study and implement the standards for college programs for adult students with brain injuries as indicated under "National Standards for College Programs", "Post Secondary Protocols", and "Post Secondary Brain Injury Programs", which are on the Brain Injury Network web site. The most important consideration for us when a post secondary facility operates a program for students with brain injuries is that it be safe.

http://braininjurynetwork.org/nationalstandards.html

http://braininjurynetwork.org/postsecondaryprotocols.html

http://braininjurynetwork.org/postsecondarybiprograms.html

Implementation of the above suggestions will help protect people with cognitive issues who are returning to college in their effort to recover from brain injury.

2. Make a review of the procedures and practices of the **California Department of Rehabilitation** regarding working with clients with brain injuries. Please find out why their track record of helping people with brain injuries procure employment is poor. The department has rigid standards on how to work with its clients. Many people with brain injuries need accommodations that the department does not offer. There must be leeway if persons with brain injuries are really going to get help from that department. Add one requirement to the basic training for vocational rehabilitation counselors who work for the Department of Rehabilitation. They need to have taken at least one if not more full length semester college level courses on the topic of brain injury if they are going to properly counsel Californians with acquired brain injuries.

3. Direct the **Department of Mental Health**, which operates the California TBI Model Project Program, to seek out survivors who are independent of its operation or any government or service provider organization to serve on its "Survivor Council". A survivor council needs to have some survivors on it. We don't think the survivor council the Department of Mental Health has meets the spirit or the requirement of the HRSA grant system that there be a *survivor* council. Having a survivor council that is devoid of independent survivor participation should also not be acceptable to the California legislature. (Incidentally, California appears to be the only state maintaining its primary TBI service modality via a Department of Mental Health.)

4. When conducting screenings of **the homeless** population include some basic questioning regarding "brain injury". We have no doubt you will find that a great many people who are homeless in California have sustained a brain injury. Armed with that information the government will do a better job of helping these people get off of the streets and into more safe, productive lives.

5. We individuals with brain injuries rely on community programs to make up for the lack of other kinds of programming for us, and **state budget cuts** are having a negative effect on local services. For example, we rely on adaptive physical education classes in local junior colleges. With the just announced state budget cuts, there will be no teacher's aides in the exercise pool. Therefore, people with

brain injuries who need an aide in the pool (and these are the people who need adaptive physical education the most) will not be able to take adaptive physical education. This is one of the only ways some people can get exercise that they need to keep their bodies toned. It also helps keep their minds sharp. Additionally, with cuts to bus services, many persons will have fewer options as to how to get around town. Cuts to In-Home Health Care mean many have to go live in a nursing home instead of living semi-independently. These types of cuts hurt the poor and the disabled. Many people with brain injuries are poor and disabled. We hope these services will be restored as soon as possible.

Conclusion.

This commentary was presented for the Brain Injury Network by Sue Hultberg, MA and JD. Thank you for the opportunity to share the Brain Injury Network's views. I welcome any questions you may have. Please contact me at survivors@braininjurynetwork.org if you have any questions.

Sue Hultberg, TBI Survivor, 1985

President, Brain Injury Network - Advocacy for and by ABI (Acquired Brain Injury) Survivors (http://www.braininjurynetwork.org)

Thesis (1996): Traumatic Brain Injury Rehabilitation and Compensation: Survivors' Perspectives (http://www.braininjurysurvivors.org)

Brain Injury Directory: (http://braininjurydirectory.net)

Survivor of Acquired Brain Injury (SABI) Advocacy Forum Moderator: (http://health.groups.yahoo.com/group/survivoracquiredbraininjury/)