

while still on active duty, took him through three military hospitals, two civilian hospitals and a DoD contracted civilian therapy center. Upon his medical discharge from the Marine Corps in July of 2006 and before his "not-so-seamless" transition into the VA system could take place, Justin had to be placed in a nursing home at our family's expense until we could purchase a home that could accommodate his physical medical needs. Justin currently lives with us and receives the majority of his medical treatment at the VA hospital in Washington DC. However, due to the inadequacies of the VA's ability to provide tailored and consistent traumatic brain injury (TBI) therapy, case management or even basic transportation to and from the hospital, we have become ever more reliant on state and community based brain injury resources to facilitate continued rehabilitative care.

It is with a four year perspective of working with the bureaucracies of DoD, TRICARE, Veterans' Administration, Social Security Administration as well as state and community based agencies, that I address the committee today, hopeful that in the coming years, more tailored care will be available for warriors with TBI.

Unique Requirements of TBI Care

Called the "signature wound" of the Global War on Terror, traumatic brain injury often requires years of both in-patient and out-patient rehabilitation, regardless of the severity of the injury. In addition, the effects of TBI are felt not only by the individual suffering from the injury, but also by their family caregivers who are often left to manage a great percentage of each facet of the service member's/veteran's daily adult life.

As the members of the committee are well aware, no two brain injuries are the same, but as medical science continues to discover and explore the plasticity of the brain and its' ability to "rewire" itself, the benefits of consistent and focused rehabilitative therapy cannot be underestimated. One of the most publicized examples of these benefits can be seen in the remarkable progress that Bob Woodruff of ABC News has made when his acute military care was augmented by constant and concentrated therapy from civilian brain injury experts. Although each brain injury requires individually adaptive treatment, what is unquestionably a significant common factor about the care and therapy for TBI is that family members or caregivers for the injured have to take on a much more complex and involved role than is found with many other war related injuries because the majority of service members or veterans are not capable of managing their own care. Brain injured people often cannot remember appointments, accurately report ailments and afflictions, keep track of the day of the week or the last time they took medications. They often cannot arrange their own transportation, or even navigate to appointment locations within a treatment or therapy facility. TBI afflicted warriors often receive a daunting flow of paperwork from the VA that must be attended to by the caregiver. Because many of these veterans are incapable of handling their personal and financial affairs, considerable time must be spent by a caregiver attending to bills, medical statements, insurance, appointment management, transportation arrangements as well as the securing and administration of large quantities of medications.

The day to day challenges of dealing with a loved one who has brain damage are truly daunting. The multitude of bureaucratic hoops that families are expected to jump through for services, can be the breaking point for that veteran's support system. Most families who are dealing with a veteran with TBI also have demands and responsibilities elsewhere. They often have other family members who need their attention and energy, they must hold down full time jobs and manage households. The stress of dealing with the TBI afflicted veteran cannot be understated. Without clear direction and support for both the veteran and the family, it is unrealistic to expect the best long term outcome for the TBI veteran.

VA Support to Families/Caregivers Dealing with the Challenges of a TBI Veteran

Although there are multiple issues that the veteran with TBI and their families have to deal with, one glaring deficiency within the VA system that routinely haunts caregivers is the VA's inability to answer this question: who is the point person in charge of the veteran's case? More specifically, which professional will help the caregiver navigate this complex bureaucratic system, which professional will know how to direct the caregiver as issues arise, which professional can they call in an emergency or at points of high stress? In short, to whom can the caregiver turn to throughout the journey that few, if any, families are prepared for? A journey that is extremely complicated, emotionally charged, and far more taxing than one could ever anticipate.

Despite all the repeated promises from the VA and attention paid by Congress to providing competent case management, the extent of my family's coordinated care assistance at the Washington VA Medical Center has only been appointment scheduling. Case management has been the sole responsibility of my family. We have had to navigate ourselves through the stove-piped departmental nature of care at the VA. We have been the ones, not VA personnel, to make trips to other VA hospitals in Tampa and Milwaukee to bring back best practices for TBI therapeutic care to our local VA hospital that is ironically located in the heart of our nation's capitol just a few miles from the Veterans' Administration headquarters. We have had to stumble onto the extensive network of brain injury expertise that resides at the state and local level that our VA hospital staff wasn't even aware of or had any knowledge of how to tap into. We have had to introduce specialists at our VA hospital in DC to the use of adaptive devices employed at other VA hospitals and push them to secure contracts with local vendors so that our son could have access to the equipment. Despite repeated requests over the past 15 months, we have yet to be directed to a medical professional at our VA hospital that will review all the medications prescribed by the various medical departments and evaluate dosages and how the medications are interacting. If a true case manager existed at our local VA, one that functioned like the experienced professionals we have found at the state brain injury services level, the VA case manager could be of tremendous value in alleviating the all too common frustration associated with the VA communication maze, the complicated medical issues and the emotional demands that families are bound to encounter as they experience recovery and rehabilitation for their brain injured veteran.

In our experience, the VA is extremely reluctant to utilize fee-for-service to tap into the extensive network of brain injury services at the state and community level. The attitude seems to be that

if adequate brain injury services are not available at a VA hospital, then accessing local services threatens the institution and/or VA funding and must be avoided. Consequently, while the VA struggles to "reinvent the wheel" of brain injury care and slowly and methodically attempts to build their own expertise, veterans needing experienced care are left in a void. Because the VA has very little knowledge or motivation to investigate what is available at the state and community level for brain injury care, it is left up to the families to discover these services on their own. In our case, the way we discovered the Virginia Department of Rehabilitative Services, the Woodrow Wilson Rehabilitation Hospital in the Shenandoah Valley, the ADAPT Clubhouse Program in Alexandria, the Tree of Life therapy center in Richmond and the extensive expertise of the private non-profit Brain Injury Services, Inc., was purely by accident, without any referral from our VA hospital.

Suggested Improvement in Care for TBI afflicted Veterans and their Caregivers

While the Veterans' Administration creates the infrastructure to deal with long term nature of proper care and therapy for brain injured veterans, there are simple changes that could be easily implemented in the near term that can be immensely helpful to families. A wiring diagram detailing the responsibilities of the different VA team members in the various medical departments that delineates their respective roles in rehabilitation, therapy and medical care would be extremely helpful.

One source document with all of the team member's phone numbers and the various departmental extensions should be provided to each family. A fistful of business cards does not suffice when families are overwhelmed with day to day recovery, therapeutic, medical, and emotional issues. A flow chart should be created that allows a family to track where to initiate the process for appointments, referrals, access to fee for outside medical/therapy service, financial, insurance and legal assistance. If and when proper case management becomes a reality at the VA, family members should be relieved of the responsibility for locating and initiating care. However, until true case managers are in place, a flow chart is an imperative.

The VA must research, have a clear understanding of, and then communicate to family members/caregivers what outside services TRICARE and/or the VA's fee-for-service program will or will not cover for a TBI veteran seeking outside therapy and care. Particularly given the new overlapping coverage between the DoD, TRICARE and the VA provided by Congress in the recent DoD Authorization Act, it is essential that the VA not require families to interpret the provisions and rules applying to outside care on their own.

Therapeutically speaking, whether it is occupational, physical, cognitive or speech, the family/caregivers need to be more active participants in both short and long term goal setting. It is common knowledge and common sense that when people are stakeholders in any process the outcome is better. Therefore, active program participation on the part of the injured veteran and their support system needs to be increased. VA medical professionals must break out of the mindset that they can inform a brain injured veteran about follow-on care instructions, home exercise routines, or future appointments and the veteran will remember what was said to him or her. A system must be instituted where a designated family member/caregiver is immediately informed through the telephone or e-mail whenever instructions or appointments for a brain injured veteran are passed.

Team meetings that include the veteran and their family members should be held initially and then augmented with regular follow-up meetings throughout the veteran's programming to facilitate communication, common goal setting and better understanding of the needs of both the veteran and the family. If functional outcomes and environmental independence are priority goals for the brain injured veteran, then it is imperative that home visits are a part of each therapist's treatment responsibilities. How else can each therapists accurately assess the veteran's environmental and functional needs outside of the clinical setting of the VA? Returning to and gaining the highest level of independent function should logically be the goal for each TBI veteran. If returning to the home environment as independently functioning as possible is the ultimate goal, then all of the team therapists need to be knowledgeable about the nuances, both physical and emotional, that the veteran with TBI is dealing with in their living environment. Simply stated, a comprehensive and supportive rehabilitative and therapeutic program can only be created when the VA health care professionals have first hand knowledge about the home environment surrounding where that veteran is living.

Most of the VA brain injury evaluations and assessments conducted on our son Justin have relied on his own personal reporting. Throughout the process of rehabilitation, Justin's report on his own condition, both past and current, has often been taken as fact and recorded as such. As a result of his extensive brain injuries, fact and fiction are often mixed and when coupled with a distorted sense of time, the result is an inaccurate reality. Therefore, if conclusive recommendations and treatment options are based on a TBI veteran's self-reporting, the result will be less than accurate and ultimately less effective. Confirmation of information from reliable sources such as family members and caregivers is vital to verifying the accuracy of information that becomes a part of that veteran's permanent file and is integral to his or her treatment plan.

Finally, the belief by some that either DoD or each and every VA hospital must create a center of excellence for brain injury must be carefully weighed and evaluated against the availability and expertise with brain injury that exists at the state and community level. There is virtually no hope that a brain injured service member or veteran will ever return to active duty. Therefore, does it make sense to surround them during their rehabilitation with the military culture? If the goal is to reintegrate the brain injured warrior into civilian society as rapidly as possible then it is only logical to contract for services wherever local experience and expertise already exists. In our son's case, we believe that continued exposure to the language, habits and behavior that is commonplace in the military and within the veterans' administration hospital environment that is clearly not acceptable in the civilian workplace, actually hampers and delays his ability to reintegrate with civilian society. It is my opinion that when brain injury expertise exists at the state and community level, the VA should do all it can to contract for that expertise rather than attempt the long process of creating in-house brain injury expertise.

Summary

Over the past four years, my wife and I have attempted to provide the best rehabilitative care for our son and pass on our "lessons learned" to the families of those heroes like him suffering from TBI. During this process we have had to call on friends and call in favors from what we call our

"legion of angels" on Capitol Hill, at TRICARE - HEALTHNET, in the military and at the VA to work the system for us to get the care our son needs. We also have utilized our own financial resources to make the right things happen for Justin. We have the blessings and good fortune of being able to call upon these resources to help our son, but we are not representative of the thousands of family members that cannot rely on "connections" and who are overwhelmed with the responsibility of caring for their loved ones with TBI. Waiting for the DoD or the VA to build the infrastructure to deal with TBI while simple standard operating procedures can be established and local resources tapped into for TBI veteran care today, should be considered unacceptable. It is my hope that by drawing attention to support provided for families caring for our warriors with TBI, you will spur the VA into action.

Chairman Akaka, Senator Burr and members of the committee, thank you for the opportunity to testify before you today and I look forward to answering your questions.