

Wounded Warrior Family Care Report

Establishing a Model of Family Support

Because Getting Them Home is Just the First Step



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Endorsement Of *The Wounded Warrior Family Care Report*

*“Military families often face challenges and make sacrifices, some on a daily basis. **The Wounded Warrior Family Care Report** will bring home to America’s citizens the scope of the sacrifices many of our military families make when their soldier returns home injured. This impacts the entire family in every aspect of their lives now and maybe forever. While they willingly become caregivers, they are often overwhelmed with the daily requirements and financial costs of caring for a severely wounded loved one. This report tells us all – citizens, corporations, lawmakers and other groups – how we can and should help to make their lives easier and truly let our soldiers and their families know that we appreciate what they have given to keep our country free.”*

**Sylvia E.J. Kidd, Director, Family Programs,
The Association of the United States Army**

*“When a soldier, sailor, airman or Marine falls wounded on today’s battlefields, our nation responds with magnificent medical treatment. War wounds, however, are endured by more than the service member; entire families are damaged, especially if recovery is extended for months, years or permanently. **The Wounded Warrior Family Care Report** identifies the often unmet needs of these households and proposes solutions. Our warriors and their families sacrificed for us. It is now our turn and responsibility to give back to them. This report tells us how.”*

**Jack Klimp, Lt Gen USMC (Ret), CEO,
Air-Conditioning, Heating, and Refrigeration Institute**

*“Navigating through the military and VA health care systems is more often than not an overwhelming challenge to the wounded warrior and their family. In addition, numerous organizations offer a myriad of products, programs and services creating yet another set of choices and decisions. Many families may be unaware of the numerous programs available to them, yet others may be deplete of the energy needed to obtain the right resources. **The Wounded Warrior Family Care Report** identifies four guiding principles and opportunities for all organizations to come together to build a better unified support system for those who selflessly defend this nation. I urge you to not only read this report, but to join us in creating a better future for our wounded warriors and their families.”*

**RADM Kathleen L. Martin USN (Ret), Executive Director,
Navy Marine Coast Guard Residence Foundation**

*“Our nation has demanded much from our service members and their families during the last few years; our military families have sacrificed daily yet proven resilient. Now is our turn to support those family members most challenged: the caregivers of severely injured service members. **The Wounded Warrior Family Care Report** captures first-hand the unique challenges faced by these families and the associated complexities of delivering services. This report serves as a call to action for all who read it. The need is great and the time is now. **The Wounded Warrior Family Care Report** shows us the way ahead.”*

Deb Mayberry, President, The Bowen Group

*“The members of our armed forces are owed a tremendous debt of gratitude for protecting the freedom that all of us hold so dear. Many have been wounded in action – some so seriously that their lives and the lives of their families have been radically and permanently changed. Family members have become the primary caregivers of their wounded warrior. **The Wounded Warrior Family Care Report** identifies many resources available to our wounded warriors and their families but, more importantly, it establishes a model of support to strengthen, and add to, those resources. The model proposed in this report will serve to put into practice the warrior ethos: ‘Never leave a fallen comrade.’ Now it is our turn ‘to care for him who shall have borne the battle.’ There is no higher priority for our wounded warriors and their families.”*

William Metzdorf, LTC USARNG (Ret), Licensed Family Therapist, D. Min

*“Hearing the words, ‘Your Marine has been seriously injured on the battlefield,’ is the phone call a family member never wants to receive. **The Wounded Warrior Family Care Report** not only helps to answer the important questions immediately following this news, but it provides an outline for action to better support the whole family unit in the weeks and months to follow. The Quality of Life Foundation is taking a leadership role to enlighten and engage those who provide support to wounded warrior families as they face the difficult challenges of providing long-term care to their severely injured service member.”*

Mary Regner, 31+ years as a USMC spouse, mother of a Marine and currently serving on the Board of Governors of The National Military Family Association

*“America has responded to the plight of severely wounded soldiers with an unprecedented outpouring of programs and assistance from both the government and the private sector. With so many resources in play, it is easy to assume that all needs are covered when, in fact, significant gaps remain. **The Wounded Warrior Family Care Report** walks with the severely injured veteran and his or her family from the time of injury forward and describes the optimal assistance for each phase of the journey. By comparing existing services with the needs expressed by the families themselves, **The Wounded Warrior Family Care Report** effectively shines light on areas where support can be strengthened. Thank you, Quality of Life Foundation, for providing this report along with the accompanying recommendations to help America provide the continuum of support our heroes and their families need to rebuild their lives after paying such a tremendous sacrifice.”*

Kathryn M. Schumacher, former director of family assistance for a military family non-profit and Army Reserve spouse for over 34 years

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The Quality of Life Foundation is a 501(C)(3) tax-exempt public charity formed to develop, support or implement strategies that improve the quality of life by enhancing the ability of individuals, groups or communities to overcome limiting barriers.

A chance meeting between the foundation's chairman, Michael Zeiders, and the spouse of a severely injured Marine was the catalyst for the Quality of Life Foundation to begin researching the unique challenges faced by families of severely injured service members with a goal of documenting what these families experience and identifying the resources they need to help them respond to this life-changing event.

From March to September 2008, the foundation conducted research and outreach that culminated in this report that clearly defines the population reviewed, their unique support needs, existing resources, and a comprehensive Model of Support for the Severely Wounded Warrior Family.

Dedication

This report is dedicated to every military family. They all sacrifice daily as their service members protect and defend our country at home and abroad.

Acknowledgements

A special thanks to Kimberly Munoz for her passion, vision and consistent commitment to provide a voice to family caregivers and objectively search for opportunities to support wounded warrior families better. Kim is deeply grateful to the countless military families who maintain the home front while their loved one is far away, facing imminent danger, to protect and serve our country. She is particularly appreciative of the sacrifices of those service members, who along with their families, face life-long challenges due to horrendous injuries suffered in service to country. It is her hope that this report will serve as a catalyst for change in how the nation provides life-long support to severely wounded families.

Special thanks also are given to Kathy Schumacher for her significant contribution to this report. Her clear understanding of the issues, desire to honor military families, and hours of careful review were invaluable.

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Introduction

There is a lot of press surrounding America's Wounded Warriors these days. High-ranking officials and celebrities routinely visit military hospitals, wounded service members are recognized and applauded at major sporting events, and Wounded Warrior Recovery Programs abound. Since the Walter Reed scandal broke in February 2007, there has been a rush of activity to improve the care of the wounded, to treat them with dignity, and to honor those who have borne the brunt of battle. This attention is good. After all, these soldiers, airmen, Marines and sailors are the ones who have endured the most personal of sacrifices; a limb, or limbs, partial brain function, mobility, and for some, their future. But there are others who also paid an incredible and personal sacrifice: their families. These families stand behind these wounded warriors, tending to them at their bedsides, helping them painstakingly recover from horrific wounds as their lives take an unexpected, uncertain direction. Family members who leave behind their jobs, their homes and their routines to stand yet again behind their service member, quietly serving our country in a support role seldom noticed, but relied on every single day. Their role is just as important as fighting on the front lines, as they hold down the home front and pick up the pieces of a shattered life when their service member returns home, irrevocably broken. These families are the focus of our study, and we present their story in this report.

Where do family members of the severely injured turn when they need a break? How do they juggle responsibilities at home, and those they face far from home, while attending to their wounded service member's needs at a Military Treatment Facility? When there are children involved, where do they turn for emotional support when both parents are fully engaged in the healing and recovery of the service member? And what happens when that service member finally leaves inpatient care and begins the outpatient phase of their rehabilitation – what programs and services buoy the family members as they take on the full brunt of caregiver responsibilities for months and years on end? What types of support are needed most by these Severely Wounded Warrior families, and are their support needs being met?

To answer these questions, the Quality of Life Foundation surveyed caregivers of severely wounded warriors to identify their unique support needs and how existing resources either met, or did not meet, those needs. We interviewed case managers who provide services to wounded service members and reviewed testimonies from congressional hearings related to the care of the wounded. From those sources, we developed a Model of Support that describes the key elements to proactive and complete support as the family works to recover from the effects of severe injuries, restore quality to their lives, and integrate into their local communities.

Our report describes the family members' experiences as their lives suddenly shift to revolve around the care and recovery of their service member. It begins with the initial phone notification of injury and continues through the transition to home and community. It illustrates the emotional, financial and physical tolls families experience as they spend months away from their own home and support networks to provide bedside care. It continues as they make the transition away from 24-hour inpatient care to home-based

rehabilitative care and the logistical and financial challenges inherent in modifying a home, obtaining accessible transportation, meeting the emotional needs of all family members, applying for federal benefits, and fulfilling caregiver responsibilities.

The following also describes government and private resources on which these families commonly rely for support as they travel this difficult path. Appendices to the report describe those resources in greater detail. In addition, as we narrate the family-member experience, we suggest a “Model of Support” that explains how to strengthen and reinforce families as they focus on their injured service member.

The hypothetical case we describe involves a parent assuming the role of caregiver for an adult child. Other cases, for example, a spouse caregiver with very young children at home are just as possible. The “Model of Support” considers all family composition possibilities.

The outstanding medical care provided by the Military Health System, on the battlefield and here at home, has resulted in service members surviving horrendous injuries that proved fatal in previous wars. Thousands of families are facing serious, life-long challenges as they bring their war-scarred service members home and begin the process of rebuilding their lives. Mothers, fathers and spouses are becoming fulltime caregivers for the seriously wounded, sometimes for a month, sometimes for the rest of their lives. How many? The following statistics provide pertinent background information as of October 2008:

1.6 million deployed¹

32,000 wounded in action²

15,000 unable to return to duty³

5,630 seriously injured (TSGLI recipients)⁴

**At least 4,448 Severely Wounded Families
need a uniquely designed
Model of Support to recover from
injuries and restore quality to their lives.**

Recipients of Traumatic Service Member Group Life Insurance (TSGLI) payments represent the most severe *physical* injuries – blindness, amputations, paralysis, traumatic brain injury, and severe burns. For purposes of this report, we assume those who suffered poly-trauma amputations, traumatic brain injury, paralysis, blindness, and severe burns will require years, if not a lifetime, of intensive family care. Based on that criterion, as of July 2008 there were at least 4,448 families who would benefit from a uniquely designed Model of Support as they assume the role of caregiver for months, sometimes years, for their critically injured service member.

It is important to note that although service members with severe PTSD (up to 14 percent of deployed)⁵ often require long-term, intensive family caregiver involvement, they are not currently eligible for TSGLI payments – and as such – not included in the estimate.

¹ http://www.rand.org/pubs/research_briefs/RB9336/index1.html

² http://siadapp.dmdc.osd.mil/personnel/CASUALTY/gwot_component.pdf

³ <http://www.defenselink.mil/news/casualty.pdf>

⁴ http://www.airforcetimes.com/news/2008/07/military_traumaticinjury_insurance_071708w/

⁵ http://www.rand.org/pubs/research_briefs/RB9336/index1.html

However, they and their families also would benefit greatly from the services described in the Model of Support.

There is no shortage of programs designed to support severely wounded families as they recover. Additionally, conversations with the people who lead and staff these programs indicate a committed network of case managers and others who continually give their very best to do what they can within the confines of their programs and government regulations. For example, each military service has implemented a Wounded Warrior Program designed to support injured service members and their families during hospitalizations and transition from active-duty military life to veteran status. Veterans Affairs (VA) case managers compliment the military services Wounded Warrior Programs as they ensure separating service members receive all eligible benefits and refer families to appropriate agencies for other support needs. Both have systems to follow up with these families after they have transitioned into their communities.

Most of America's wounded and their families are served quite well by these resources. However, the most catastrophically wounded families (less than 15 percent of those wounded) need more. They need services and programs that are designed to address their specific family needs. Programs designed to prevent emotional, financial and physical exhaustion, versus programs that respond to crisis situations. Services that provide complete and accurate information to families regarding treatment and rehabilitative options that are patient-centered and focused on restoring the highest level of independent living to the veteran. Before discharge home, families need uniquely tailored accommodations, training, and integration plans to ensure they have: a safe, accessible home; reasonable access to rehabilitative care, and a support system that connects them with resources to facilitate community integration, employment, and if needed, long-term assisted-living arrangements for the veteran.

The unique support needs of catastrophically wounded families were identified in the Dole-Shalala Commission on the Care of the Wounded. In response, the VA and DoD jointly launched the Federal Recovery Coordinator (FRC) Program in January 2008. The FRC Program was designed to streamline access to federal benefits and coordinate private-sector supports for seriously wounded service members and their families. The FRC coordinates federal health-care teams and private community resources to achieve personal and professional goals identified in an individualized recovery plan developed with the veteran and his/her family.

This program is an impressive step forward in support of severely wounded families. However, the program's effectiveness is limited by understaffing and federal regulations. As of September 2008, only 119 families were enrolled in this program staffed by eight full-time coordinators.⁶ In addition, federal regulations restrict FRCs from requesting assistance for families from non-governmental organizations, which means their "coordination of private community resources" is limited to referring families to them or advising an organization that a need exists. To provide the most help to a severely wounded family, case managers must have adequate time to engage fully with them, help them

6 Stars and Stripes, Pacific Edition, Oct. 2, 2008, "Catastrophically Wounded Gain Life Long Advocates," Tom Philpott

anticipate their needs, explain the processes for obtaining services and supports, investigate community-specific resources, and follow up on actions initiated. In addition, they must have resources to meet urgent needs. Federally-funded case managers do not have direct access to funds to meet this type of short-term need. Instead, they must identify an existing community resource and refer the family to it. Finally, as case managers work with the family to make the transition from hospital to home, they must have sufficient time to conduct home visits to fully understand the family's unique life situation to allow them to develop a realistic and achievable transition plan. They must also investigate thoroughly, and connect families with, local resources to meet the goals of that plan.

This report concludes with recommendations to strengthen existing resources and develop new supports to supplement existing Wounded Warrior and Federal Recovery programs. While we do not yet have all the answers for how to implement fully the Model of Support, this report provides a framework we all can consider (government and non-government organizations) as we examine existing programs for improvement and develop new resources to provide the most proactive and meaningful support to these families.

Collectively, our country must shift our position from reactive to proactive support of families from the time of injury, throughout transition home and beyond. These families paid, and continue to pay, a hefty price in service to this country. We all benefit from their service as we enjoy living in a free and secure America protected by our military community. We all must give our full measure to help shoulder the burden of their sacrifices.

Part 1: Establishing a Model of Support

The SPC Brown Family Story

The Brown Family

Family Composition

Two parents, both employed full time,
Three children, two minors living at home
in Augusta, Ga., one adult son injured in
Iraq.

Service Member

Single, 22-year-old Army SPC
Severely wounded by IED

TBI, Amputation, PTSD

Landstuhl	two days
Walter Reed	16 months
VA Hospital	six months
Outpatient	30+ months

Specialist Brown, a single, 22-year-old Army soldier, was severely wounded in Iraq. He was initially medevaced to Landstuhl Regional Medical Center in Germany, and then transported to Walter Reed Army Medical Center in Washington, D.C. After 16 months of medical care for a severe Traumatic Brain Injury, an above the knee amputation, PTSD and shrapnel wounds, he was transferred to a VA Polytrauma Center in Richmond, Va., for further inpatient treatment. After 6 months, SPC Brown was released to a VA Polytrauma Network Site in Augusta, Ga., near his family's home. He currently lives with his mother, father and two brothers.

The Brown Family

Family Caregiver

Responsible for oversight and
administration of all medical, mental
and daily-living functions for service
member.

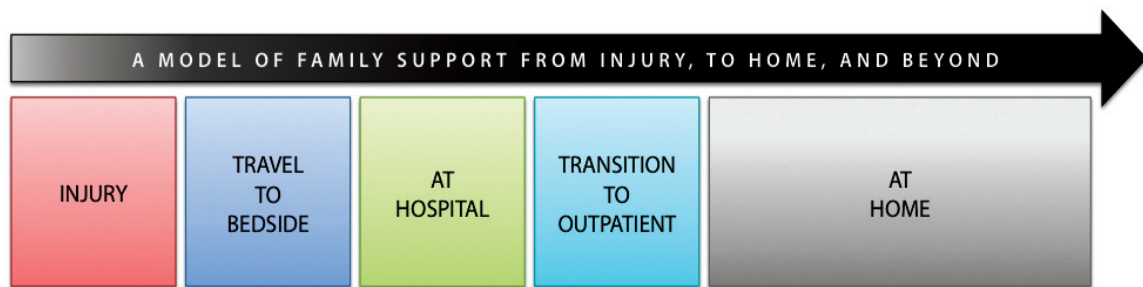
Service Member

Currently dependent on family
caregiver for all daily-life activities and
likely will require life-long Aid and
Attendance.

Almost 2 years after his catastrophic injuries, SPC Brown is unable to live independently and relies on his family for many daily activities. The severe TBI robbed him of many basic life skills, such as short-term memory, the ability to focus, to balance, to walk unaided, to control emotions, to speak clearly, and to reason. Mrs. Brown attends appointments with her son to receive and relay treatment information and coordinate his medications. SPC Brown's outpatient care primarily treats TBI and PTSD issues; he attends three days a week. He also attends monthly appointments for amputation and prosthetics care.

Model of Support Diagram and Boxes Explained

The following pages describe the Brown family experiences, given today's environment, as they journey through five different phases of a long and difficult road to recovery. From injury notification, to travel to a military treatment facility, through providing bedside care at the hospital, through the transition to home-based care and then finally, to community-based living.



After each description of the family experience, we outline a Model of Support designed to provide the tools and resources families need to stay strong while they respond to their loved one's catastrophic injury. We highlight the elements of each phase of the Model of Support with a grey text box. Elements that are not currently in place, or have suggestions for improvement, are denoted with an asterisk and highlighted in blue. Elements that are already in place are denoted with a green checkmark.

Listed below is an example:

Model of Support

✱ Denotes a suggestion for improvement to a currently provided support or implementation of a new support.

✓ Denotes an element of the Model of Support that is currently provided.

Injury Notification – Family Member Experience

"Mrs. Brown, this is LTC Jones with the United States Army. I am calling to notify you that your son has been seriously injured in Iraq and is now at Landstuhl Regional Medical Center in Germany. He is in stable but critical condition and will be transported to Walter Reed Army Medical Center in the next couple of days. He will need you to join him at Walter Reed. I do not know how long you will need to stay, but plan for at least two weeks."

Imagine you are at home, watching television, and you hear the phone ring. Imagine hearing the words you just read, but picture your own loved one. Think about how this phone call sets in motion a nightmare many families fear will come true when they say goodbye at deployment. Now, think about the Brown family. One minute, all is well; the next, their life and their son's life is changed forever.

Mrs. Brown ends the call with travel-arrangement information and relays this horrible news to her husband. As they hurriedly prepare to leave, questions regarding their son's condition, how he was injured, and whether he will survive, flood their minds. Shock, fear, anxiety, despair and grief come in waves – they want to drop everything and run to their son's bedside - but must first take care of things at home. At a minimum, the Browns must:

- *Prepare their home for a two-week absence (pay bills, stop mail, arrange for lawn care, arrange for pet care, etc.).*
- *Inform their other children and arrange for their care (notify schools of contact information for local guardian, sign medical releases for their children, etc.).*
- *Notify extended family.*
- *Arrange time off from their respective employers.*
- *Cancel pending appointments.*
- *Pack clothes, medications and other necessities for a minimum two-week stay.*
- *Arrange transportation to the airport.*

They have taken just the first step in a long journey to bring their son home. The Model of Support suggested on the next page seeks to make this first step a little easier.

Injury Notification - Model of Support

Injury notification is the first chance to set a stage of empathy and support. Accordingly, a local Assistance Officer (AO) notifies the family, by phone, of the injury and then schedules an in-person follow-up meeting to provide assistance as the family prepares to travel to the service member's bedside. A chaplain (or equivalent) accompanies the AO for the initial meeting. The AO is a fully trained military member with the experience and knowledge to provide relevant information and answer any questions the family may have. The AO briefs the family on travel arrangements and what to expect at the hospital. Recognizing that emotional trauma affects a person's ability to think clearly and retain detailed information, the AO provides the family with a specially designed notebook with sections for recording points of contact, writing notes, storing business cards, recording expenses, and storing receipts. This notebook also includes a checklist for the family to use as they prepare to leave their home – to help ensure important matters that need attention in their absence are covered by a neighbor, relative or friend. The AO arranges transportation to the airport. The AO provides the family with a Point of Contact (POC) at the receiving hospital and notifies that POC when the family departs.

Model of Support During Injury Notification

- ✱ Assign an Assistance Officer to provide notification and in-person support (accompanied by a chaplain) prior to travel to hospital.
- ✱ At notification, provide a notebook with preparation checklist, generic forms, and other items to help prepare family for extended absence. Notebook also will be used as a reference guide during service member's extended medical care.
- ✓ Coordinate transportation to airport.
- ✓ Provide Point of Contact at receiving hospital and ensure positive hand-off after family departs home station.

Travel to Bedside - Family Member Experience

Mr. and Mrs. Brown's air travel to Washington is arranged and paid by the Army. They are met at the airport by a military escort who transports them to Walter Reed Army Medical Center. When they arrive, they do not yet know lodging arrangements. Their minds are filled with more questions than answers as they anxiously anticipate the moment they see their son and learn the extent of his injuries. So far, they have paid for a cab ride to the airport, a meal away from home, and left cash with a relative to cover expenses for their other children.

Once they get to the hospital, they experience a rush of emotions and are not in the best position to absorb new information or remember logistic details. Their first priority is to see their son. Their first reaction is a mixture of shock, grief and anxiety, all accompanied by relief that he is, at least, alive. It takes time to adjust to what they have seen. They wish it was all a mix-up and that somehow all this would go away. They need time to process what has happened, to grieve the loss that these severe injuries represent. However, now is not the time. Instead they must get to the business of providing care and encouragement to their son, establishing a "home base" near the hospital, and coordinating care at home for their other two children. Mr. and Mrs. Brown are taken to the Soldier and Family Assistance Center (SFAC)⁷ where they learn their lodging arrangements and are introduced to several contacts who can help them with issues they may face during their stay. They are given a "Walter Reed Hero Handbook" that provides area information, a guide to the hospital, and other relevant information. Within the next few days, they will meet a Hospital Social Worker and an Army Wounded Warrior (AW2) Program⁸ Soldier and Family Management Specialist (SFMS) who has been assigned to their family.

While nothing could make this stage easy, AW2 and SFAC staff and hospital support resources do a great job surrounding the family with services and people to help them cope. The Model of Support described on the next page reinforces practices already in place and includes just one suggested improvement.

⁷ See Appendix A, page A5 for further detail regarding the Soldier and Family Assistance Centers.

⁸ See Appendix A, pages A2- A3 for further detail regarding the Army Wounded Warrior Program

Travel to Bedside – Model of Support

The Model of Support during Travel to Bedside maintains the in-person support established at Injury Notification, continues to consider the emotional state of the family, and minimizes out-of-pocket expenses. Travel to the hospital is coordinated and prepaid. In addition, an advance per diem (in this case, two weeks' worth) is provided to the family members before they leave home to cover the expected cost of food and incidental expenses. Family members are met at the receiving airport by military personnel and escorted to the hospital to meet their Point of Contact (established earlier with their AO) and then see their service member. A knowledgeable medical staff member briefs the family on what to expect, and a chaplain is present to respond as needed.

After seeing their loved one, family members meet again with their POC who provides clearly written information regarding their stay (lodging arrangements, per diem rates, transportation, guide to hospital, contact lists, etc.). The POC explains the different case managers assigned to the family and the role each has (an AW2 SFMS, a Federal Recovery Coordinator - FRC, etc.). The chaplain remains available at this time.

Model of Support During Travel To Bedside

✱ Advance per diem to minimize out-of-pocket, reimbursable expenses.

- ✓ Prepaid travel, military escort from airport to hospital.
- ✓ Positive connection with hospital Point of Contact.
- ✓ On site, available chaplain, regardless of time of arrival.
- ✓ Clearly written details for lodging, meal and transportation logistics.
- ✓ Explanation of varied case managers and their roles.

At Hospital - Family Member Experience

Mr. and Mrs. Brown are both at their son's bedside for the first few weeks. After that, Mr. Brown returns home and Mrs. Brown stays with their wounded son. At a minimum, Mrs. Brown meets three case managers - the AW2 Program SFMS, a Hospital Social Worker, and a VA/DoD Federal Recovery Coordinator⁹ (FRC). During the next 22 months, she turns to each of these people for varied issues, with the FRC designated as the overall coordinator. Because SPC Brown's condition renders him unable to manage his own financial and other normal life responsibilities, Mrs. Brown must assume legal guardianship for him and requires legal assistance to do so. Mrs. Brown spends the majority of her time at the hospital – "down" time is spent in her room at the Fisher House, a temporary residential facility that provides cost-free lodging to families of patients at military and VA hospitals. Meal costs are reimbursed via a per diem system. The staff from the SFAC helps with paperwork to ensure timely expense reimbursements, prepaid lodging, and necessary travel orders. The AW2 SFMS also periodically checks on Mrs. Brown. As her son's doctors communicate his condition, Mrs. Brown has two choices: to spend hours researching alternative treatments for his injuries and then decide whether she agrees with the doctor's recommendation; or simply to trust the doctor's guidance and follow it. She learns how best to help with his recovery and how long-term effects may impact his military career. She meets with doctors during daily rounds to discuss the latest changes in her son's medical condition. Mrs. Brown uses her cell phone to stay in touch with her husband, children and extended family. She develops relationships with other caregivers at the hospital. However, she still feels, at times, very isolated and alone. While the AW2 SFMS works diligently to advocate for SPC Brown and his family, Mrs. Brown still feels an overwhelming responsibility as she considers medical-care issues and long-term implications of SPC Brown's probable separation from military

Family Caregiver Experience

Lives away from spouse and other children, in small space, for 22 months.

Assigned multiple case workers.

Assumes legal guardianship for service member.

Learns extent of injuries, treatment options and prognosis.

Spends every day with service member to ensure his needs are met.

Learns service member likely will require long-term care and be discharged from the military.

Updates extended family members on condition and progress.

At times, feels isolated and emotionally exhausted.

Is initially intimidated by the responsibility of total oversight for service member's overall well-being.

Attends hospital support groups when possible.

Researches alternative treatment options for injuries.

⁹ See Appendix A, page A12, for more details on the Federal Recovery Coordinator Program.

service. Mrs. Brown faces a wide range of emotions, as she comes to terms with the permanent changes that have occurred in their lives. When she feels comfortable leaving her son's bedside, she attends hospital support groups; but sometimes her overwhelming responsibilities keep her from realizing she needs emotional support. She is comforted by the weekly dinners and other encouragements provided by local non-profit organizations. Upon seeing a flier advertising Military OneSource¹⁰, she contacts them to seek further emotional support. She is referred to a counselor for a maximum of six sessions and finds some relief after attending.

Family Caregiver Experience

Worries about spouse and other children, living at home – desires to see them.

Learns that son will receive large, lump-sum TSGLI Payment. (Offered financial-management class in conjunction with payment).

Loses job as a result of extended absence, also loses employer-paid health, dental and life insurance.

Requires medical and dental care.

Incurs expensive cell-phone bills.

Needs respite.

Experiences marital strain.

Misses “big days” such as graduation, birthdays and holidays with other family members.

Worries about loss of income.

Hesitant to use TSGLI money and prefers to reserve it for long-term care expenses.

Mr. Brown, holding down the “home front,” also faces emotional and logistical challenges as he works full time and takes care of their home and other children. He is pulled in two directions: one to support his wife and help care for his wounded son; the other to continue earning an income and ensure his other sons have the care and support they require. SPC Brown receives a lump-sum TSGLI payment ¹¹ of \$75,000, intended to help offset unexpected expenses that accompany traumatic injuries, along with an invitation to a financial-management class.

Mrs. Brown eventually loses her job as a result of her extended absence – along with that, she loses her employer-sponsored medical, dental and life insurance. During the 22 months she is away from home, Mrs. Brown misses at least one, and sometimes two, family members' birthdays, her wedding anniversary, many holidays, and a high school gradu-

ation. She considers ignoring her own “wellness” care (i.e., annual screenings and check-ups) due to travel costs and logistics challenges of providing bedside care to her son. However, she longs to be home and reconnect to her other children. She gets assistance from staff at the SFAC to arrange her travel home and her husband's travel to Walter Reed. She learns that to keep her same room and avoid packing all her things, she must

¹⁰ See Appendix A, page A6-A8 for more detailed information regarding Military OneSource resources

¹¹ See Appendix A, page A14, for more details on the TSGLI Program.

not leave it vacant. She and her husband spend a day together at Walter Reed before she leaves for home. Their relationship has been tested while they have lived separate lives, each operating as a single parent, miles apart, with tremendous responsibilities. They recognize the need to keep their family bonds strong as they look to a life-long future of caring for their war-injured son, but they are not sure how to do that. Financial hardship (as a result of Mrs. Brown's lost income) adds to an already-stressed family. The Browns are hesitant to use any of the \$75,000 TSGLI payment to offset their lost income as they want to reserve it for potential long-term care needs for their son. Mrs. Brown enjoys the short visit, reconnecting with her other children and neighborhood supports. As she packs her suitcase to return to Walter Reed, she wonders how long it will be until she returns home for good. Her sons wonder the same thing.

Shortly after her return, Mrs. Brown learns her son has been declared "unfit for duty." The AW2 SFMS carefully explains how this will affect her son's income, separation pay, and transition to the VA system. The FRC explains VA disability compensation¹² and other benefits and grants for which SPC Brown is eligible. The complexities of how to apply for and receive the maximum benefit and grant amounts seem incomprehensible at times. Mrs. Brown relies on her AW2 and FRC contacts to help obtain the maximum grants and benefits her son has earned. As her son makes the transition from active duty to disabled and then again as he moves to veteran status, she prepares for the possibility that SPC Brown's income will not meet his current obligations. Mrs. Brown plans to use some of the TSGLI award to cover his financial obligations if needed.

Family Caregiver Experience

Learns processes related to separation from military and transition to VA.

Relocates from Walter Reed Medical Center to the VA Polytrauma Center at Richmond, Va.

Establishes new temporary residence in Richmond.

Adjusts to another new environment, medical team, and care-giving procedures.

Learns new rehabilitative therapies.

Receives updated prognosis and long-term treatment plans.

Desires to research alternative treatment options.

After 16 months at Walter Reed, SPC Brown's acute medical issues are met, and he is transferred to the Hunter McGuire VA Hospital in Richmond, Va., for continued inpatient rehabilitation-focused care. Mrs. Brown relocates from her room at the Walter Reed Fisher House to a hotel room near the VA Hospital in Richmond. The AW2 SFMS and FRC stay in phone contact with Mrs. Brown after the move and connect her with the OIF/OEF VA case manager assigned to her son. Mrs. Brown assimilates to a new area, new hospital, new doctors, and new peers. She works closely with the VA medical staff to learn

¹² See Appendix A, pages A15-A18 for more detailed information regarding VA Disability compensation and other benefits.

new rehabilitative therapies, what they are designed to address, and how she best can support her son's rehabilitative process. She continues to learn about the long-term effects of her son's injuries and the possibility that he may never again be able to live independently, hold a job, be a husband, or become a father. She again faces a decision either to accept what she is being told about his prognosis and follow doctors' recommendations, or believe other alternatives exist and begin a quest to find them. She continues to do the best she can to strengthen and care for her son.

Now we will discuss how to build on existing resources and case managers' diligent efforts to more proactively and fully support family caregivers at bedside, and family members back home, while their service member is receiving inpatient care.

At Hospital – Model of Support

The Model of Support throughout this phase recognizes that both Mr. and Mrs. Brown, and their other children, require the following categories of support which we will discuss in further detail:

- Financial
- Lodging
- Respite
- Emotional
- Educational – Medical Condition
- Educational – Military-to-VA Transition
- Communication
- Relocation

Financial

When a family loses a portion of their planned income and benefits, it quickly can lead to financial ruin. When a caregiver loses their job to provide bedside care to his/her service member, financial consideration for resulting lost income and benefits helps prevent the family from becoming financially desperate.

After a caregiver has exhausted their paid leave (vacation, personal time, etc.), replace their monthly income until he/she is able to return to work. Replacing lost caregiver income allows families to avoid bankruptcy as they stay current with their own financial obligations and preserve the service member's TSGLI payment for expenses related to his/her care.

In addition, if the caregiver (and by extension, their family members) also loses medical, dental and life insurance, provide insurance that will allow them to receive covered medical, dental and mental-health services within the region where they currently reside. Replacing lost insurance provides relevant access to medical and dental care and helps prevent the caregiver from going without proper care (or incurring an expense to travel home for medical/dental care). Replacing lost life insurance provides some peace of mind that in the event of caregiver death, the family will have their needs met.

In recognition of the added financial stress to the family, offer financial-management courses that teach spending and saving techniques for maximizing resources.

Model of Financial Support While at Hospital

- ✱ **Compensate for lost income.**
- ✱ **Replace lost medical, dental and life insurance.**
- ✓ **Provide financial-management courses and literature.**

Temporary Lodging

The family caregiver requires a place to call "home" during the inpatient phase. Provide prepaid lodging as close to the medical facility as possible, in a safe area, with easy transportation to and from the medical facility. Lodging should be provided - in one place - for as long as the service member needs the family member's assistance. If a family member has to return to their home base for a short time, they should not be forced to forfeit their lodging and re-establish a new place when they return.

Model of Temporary Lodging Support While at Hospital

- ✱ **Provide semi-permanent, prepaid lodging (minimize temporary lodging changes) with easy transportation to and from medical facility.**

Respite

Caregivers can begin to feel isolated when they are away from their own home and family for extended periods of time. Provide monthly opportunities to travel home (or bring someone from home to the hospital) for a couple of days. Travel expenses should be prepaid, and existing lodging arrangements should remain in place.

Model of Respite Support While at Hospital

- ✱ **Prepay travel expenses and, if needed, provide attendant for service member.**
- ✱ **Retain caregiver lodging arrangements during short respite absences.**
- ✓ **Provide opportunities for family caregiver respite and recreation.**

Emotional

The caregiver, as well as the family members remaining at home, is experiencing a most stressful situation – the traumatic injury of a loved one that will change all of their lives forever.

Assign a carefully selected and fully trained mentor to those caregivers who would like one. Mentors should be someone who has been through a similar life experience and can provide advice, guidance, empathy and understanding.

Provide on-sight, walk-in counseling services at all medical treatment facilities for caregivers via chaplains and other professional counselors. Encourage use of these services through aggressive marketing.

If long term counseling is needed, provide regularly scheduled services with one provider, until their emotional needs are met. This may require more than the maximum six sessions allowed by current Military OneSource Resources.

For family members remaining at home, provide paid access to local and responsive care with a counselor who can provide care as long as needed.

Model of Emotional Support While at Hospital

- ✱ Assign a mentor to family caregiver, if desired.
- ✱ Provide prepaid responsive, accessible counseling services to family caregiver at hospital, and to family members at home, through any available network for as long as the family needs it. ([Not contingent on family member eligibility for TRICARE or other government-funded service](#)).
- ✓ Provide on-site, walk-in counseling services at all medical treatment facilities.

Education – Medical Condition

Family caregivers are thrust into learning things they never would have imagined – especially as it relates to their loved one’s medical condition, medical procedures, and long-term prognosis. Recognize that given the trauma of the situation, family members initially may not have the capacity to remember complex medical information. Always provide such information in clear, concise and accurately written form.

Provide comprehensive training for performing procedures and managing the overall care for the service member; include symptoms and deficiencies that might emerge over time. Upon successful completion of the training, issue a certification to the family caregiver that identifies them as a DoD/VA-certified provider of services – which in turn should make them eligible to receive Aid and Attendance compensation from the VA.

Host monthly educational seminars at VA hospitals and MTFs to supplement physician-provided information. (Topics could include Alternative rehabilitative treatment strategies for severe TBI, advances in prosthetics, emerging treatments and potential benefits, etc.).

Many caregivers may desire to research alternative treatment options. Facilitate that research by providing a listing of pre-screened Website resources, with a synopsis of each organization's services. Provide Internet access in convenient locations; consider placing computers in hospital rooms.

Early and thorough rehabilitative care is a critical component of the service member's recovery as it relates to helping him/her attain the highest possible level of independent living. Due in large part to the increasing numbers of service members with Traumatic Brain Injury, many hospitals and other private-care facilities are researching new rehabilitative treatments. However, family members generally are presented only with those treatment options employed within the military and VA health care systems. As a result, some may not know that other treatment options, and facilities, exist within the realm of their service member's covered medical services. In the VA system, this is called "fee-based" services. Active duty service members access private care through TRICARE coverage.

Provide family members a non-biased analysis of the pros and cons of seeking care from different sources (e.g., private treatment vs. VA treatment). In the event a family desires to seek treatment outside the military or VA health care systems, fully explain the family's out-of-pocket costs associated with that decision and create a transition plan to get them there as quickly and efficiently as possible. The goal is to provide an opportunity for the family to make an educated decision regarding where to seek medical and rehabilitative care for their service member.

Model of Medical Education Support While at Hospital

- ✳ Provide comprehensive caregiver training regarding care, short and long-term prognosis, and treatment plans, accompanied by clearly written details and a VA certification upon completion of training – to allow caregiver to become eligible for VA compensation.
- ✳ Facilitate caregiver's desire to research alternative treatments via pre-screened list of Websites and easy access to Internet-connected computers.
- ✳ Fully inform family member of non-MTF and non-VA provided care.
- ✳ Fully inform family member of procedures to obtain care outside the Military and VA health care systems, the potential costs of that decision, and how to maximize benefit from TRICARE or fee-based VA coverage.
- ✓ Provide monthly supplemental educational seminars at all MTF and VA facilities.

Education – Military to VA Transition

Almost every change to a service member's status results in a change to his/her entitlements, pay, and/or benefits. Whether it is a change in unit assignment (i.e., transferring from a unit in theatre to a Warrior in Transition Unit), a change in active-duty status (i.e., from active duty to temporarily disabled), or a separation from service (i.e., a medical retirement or discharge). As guardians, caregivers need to understand the impact of a change in military or veteran status as it relates to income and other benefits. For example, will a proposed change result in a lower monthly income for the service member or a disqualification for another benefit or affect whether the service member is eligible for VA benefits? Will it change where he/she is authorized to receive medical care? How will a declaration of incompetence on the part of the service member affect the caregiver's ability to manage their loved one's care and finances independently? Currently, family members rely on Wounded Warrior Case Managers, OIF/OEF Case Managers, and FRCs intricate knowledge of the military and VA Benefits to explain these kinds of issues, to maximize benefits and income, and streamline application processes. Case managers must be trained thoroughly and afforded the appropriate amount of time to ensure the family caregiver understands the impacts of different courses of action, allowing him/her to make educated decisions and anticipate changes accurately.

Model of Military to VA Transition Education Support While at Hospital

- ✱ Military Service Wounded Warrior Case Managers, OIF/OEF Case Managers, and FRCs must be trained-fully and **afforded enough time to spend with families** to ensure they have complete, accurate information regarding impacts of different courses of action.

Communication

When caring for their service member, caregivers need to update and connect with family members. Cell-phone and long-distance minutes add up quickly. For those who desire to communicate electronically, provide access to a computer with Internet capabilities. For those who prefer phone communication, provide a monthly allowance to cover reasonable costs.

Model of Communication Support While at Hospital

- ✱ Provide resources (Internet and phone) to allow family members to update and connect with extended family. Consider placing Internet-connected computers in hospital rooms.

Relocation - One Medical Treatment Facility to Another

Moving from one temporary residence to another (i.e., from the Walter Reed Fisher House to a hotel near the Richmond VA hospital) requires coordination and expense. Coordinate the move, arrange lodging, and prepay expenses. Identify a receiving Point of

Contact who will provide an orientation that includes clearly written logistics and contact information.

Model of Hospital to Hospital Transition Support

- ✓ Pre-arranged, pre-paid move to new temporary residence.
- ✓ Positive connection with new POC and orientation at receiving medical facility.

Transition to Outpatient - Family Member Experience

Family Caregiver Experience

Excited to be leaving hospital.

Learns current long-term prognosis for son.

Learns procedures for taking care of son's physical needs.

Considers options for outpatient care (VA vs. private care).

Decides on VA Polytrauma Network Site near home.

Concerned about the following in preparation for going home:

- Home modification.
- Automobile adaption.
- Family emotional needs.
- Medical supplies.
- Transition to new medical facility and staff.
- Personal emotional needs.
- Daily Aid and Attendance needs of son.
- Emergency situations.

After 22 months of inpatient treatment, SPC Brown is released to outpatient treatment. Mrs. Brown learns her son's long-term prognosis and the types of care he will need as he continues his recovery. She learns additional quasi-medical procedures to perform at home. She learns where, within the VA system of care, outpatient rehabilitation treatment is available. She researches private-care alternatives. Given the needs of her family and the assurance of quality care within the VA Polytrauma System, she and Mr. Brown ultimately decide to transition to outpatient care at a VA Polytrauma Network Site in Augusta, Ga. This move allows close proximity to SPC Brown's treatment site and enables the family to live together again in their own home, maintaining the younger children's stability in neighborhoods and schools they already know.

As she contemplates their homecoming, Mrs. Brown wonders if her son eventually will recover to the point where she can return to work. She considers how

her other sons will react to the significant changes they will experience when their brother comes home. She worries about making sure she, her home, and the rest of her family are prepared to bring SPC Brown home. She considers home modifications to accommodate SPC Brown's disabilities and worries about transportation issues (how to get her son in and out of their car); medication and supplies (ensures ample supply of both for move home and plans for when and where to obtain refills); family preparation for SPC Brown's homecoming; and the adequacy of the new treatment site in Augusta, Ga.

Mrs. Brown works with her OIF/OEF Case Manager and her FRC to coordinate the move home. They provide guidance on obtaining VA grants and benefits and other federal resources. During this process, Mrs. Brown completes more applications to obtain additional VA grants and benefits. Given the current backlog at the VA and the lengthy review

process, there will be a delay in receiving benefits from some of the programs. Those that are priority for the Brown family are “Aid and Attendance,” “Specially Adapted Housing Grant,” and “Special Monthly Compensation.”¹³ These three benefits could provide significant relief as the Browns welcome their son home. Mrs. Brown finds it difficult to determine, on her own, whether or not her son is eligible for Aid and Attendance due to income and asset limitations. She learns that the Housing Grant, if approved, will be managed by a VA Housing Specialist who will identify necessary changes and hire a VA-approved contractor to perform the work. She also learns that, if approved, the grant will be paid directly to the VA contractor and cover not more than 50 percent of the cost of the modification. In addition, because SPC Brown does not own the home (his mother and father do), the maximum grant amount is \$14,000. Concerned that the VA may be unable to complete necessary home modifications before their son’s arrival, Mr. Brown researches non-profit assistance. He begins his search at a Website to which he was referred called “America Supports You.”¹⁴ Under the link “Help for the Wounded,” he finds an alphabetic listing of over 140 non-profit organizations. As he clicks on the links, he finds that although many provide meaningful support to various military and veteran populations, most do not offer assistance to modify homes. He applies with those that do. Running out of time and energy, the Browns use the remaining TSGLI funds to complete the necessary modifications before their son’s arrival.

Family Caregiver Experience

Works with FRC and OIF/OEF case managers to complete applications for:

- Aid and Attendance
- Specially Adapted Housing Grant
- Automobile Adaption Grant
- Special Monthly Compensation

Experiences concern about the complexity surrounding grant and benefit applications and eligibility requirements – as well as potential wait time between application and award.

Researches American Legion Heroes to Hometown Program.

Learns limitations of VA Housing Adaption Grant and researches available support from non-profit organizations to try to modify home before arrival.

Mrs. Brown hears about the American Legion Heroes to Hometown program¹⁵, a partnership between DoD and the American Legion that depends on Legionnaires to coordinate welcome-home celebrations and community resources to help the severely wounded reintegrate into their community. Mrs. Brown “googles” American Legion, Augusta, Ga., and finds their Website; unfortunately, it has no Heroes to Hometown information and appears to have been updated last in 2005.

¹³ See Appendix A, pages A15-A18 for more details on VA benefits

¹⁴ See Appendix B, page B1 for more details on America Supports You

¹⁵ See Appendix A, page A7 for more details on the Heroes to Hometown Program

Next we describe the Model of Support for this stage of recovery that is a comprehensive plan to anticipate and meet family-support needs required for a successful transition home. Emphasis is on preparing the family and home environment to meet family and veteran needs and to identify and connect with local resources.

Transition to Outpatient - Model of Support

The Model of Support at this phase sets the stage for success by facilitating a smooth transition home and connecting the family with valuable community resources. Case-manager involvement with the family is extensive beginning with at least one home visit to develop a tailored plan for a successful homecoming and eventual community integration.

As stated earlier in the report, rehabilitative care is a critical component of the service member's recovery as it relates to helping him/her attain the highest possible level of independent living. During the inpatient phase, family members should have learned that they have options to receive treatment outside of the military and VA health care systems. At this time of transition, it is important to support the family member's need to revisit those options as they decide the best place to seek care for their service member. Again, provide a non-biased analysis listing pros and cons for seeking care from different sources (e.g., private treatment vs. VA treatment). In the event a family believes more effective treatment is available outside of the military or VA health care systems, their FRC fully explains the out-of-pocket costs associated with that decision and creates a transition plan to get them there as quickly and cost-efficiently as possible. The goal is to allow the family to make an educated decision regarding where to take their service member for medical care.

Most severely injured service members have multiple medical conditions. Provide the caregiver complete and accurate written documentation for each condition. This documentation includes, among other things, written instructions for any procedures for which the family caregiver will be responsible, signs of emerging problems specific to each condition, medications prescribed for each condition, and an overall master list of all medications.

Case managers help families submit, and then monitor the progress of, applications for all benefits and grants that are critical to a successful transition home as early as possible (e.g., Home Modifications, Aid and Attendance, and Special Monthly Compensation). These resources must be available for the families in conjunction with their move home, not months later.

In recognition that local community support is critical to successful integration, case managers work proactively to connect families with state and local resources. This can be accomplished during the home visit. Examples include State Veterans Affairs offices, local Social Security Administration offices, local non-profits, and Veterans Services Organizations.

Case managers also facilitate access to available services from local and national non-profit organizations. Currently, family members can spend hours viewing each of the 143 organizations listed on the America Supports You (ASY) Website to find a non-profit

that serves people in their community with the type of assistance they need. While ASY is a good program, improvements are needed to reduce the amount of time a family must spend to find a non-profit that might be able to help them. ASY might consider providing an automated system that would use input data (location, type of assistance needed, service member's branch of service, etc.) to select from a large database of operational non-profits those that best match the family's needs.

It is important to note that DoD just launched the National Resource Directory in November 2008 to provide wounded, ill and injured service members and veterans, their families, and families of the fallen a Web-based directory of resources. Users input their state and select up to six areas of support, and the directory returns a listing of links to federal, state and local governmental agencies; veterans service and benefit organizations; non-profit organizations; and academic institutions, professional associations and philanthropic organizations that match the input. This is a good step; however, further refinement in the input process (e.g., adding city, type of assistance requested, branch of service, and other criteria as inputs) may provide a more easy-to-use resource listing for families who already are short on time.

Every military family faces reintegration challenges when their service member returns from deployment. How much more complicated is reintegration when compounded by severe, life-altering, physical wounds? In recognition of this, proactively offer and arrange a pre-homecoming counseling session to help prepare family members for the pending change and to evaluate the need for future family counseling. Provide follow through care as needed.

Model of Support During Transition to Outpatient

- ✳ **Home visit**, increased case-manager involvement, development of family-tailored community-integration plan.
- ✳ **Fully inform family of how to obtain non-MTF and non-VA care, the potential costs of that choice, and how to maximize TRICARE or VA fee-based coverage.**
- ✳ **Proactive approach** to applying for VA benefits and grants to accommodate family's home-living needs and to connecting family members with local VA, Social Security, Veterans Service Organizations and other local resources.
- ✳ Facilitate connections to relevant non-profit organizations - **remove the burden of research from the family caregiver.**
- ✳ **Arrange a "pre-homecoming" counseling session for family members.**
- ✳ **Evaluation of additional emotional-support needs for family, follow through care as needed.**
- ✓ **Complete written documentation for each medical condition covering: symptoms of potential emerging issues, medications, and rehabilitative therapies.**

At Home - Family Member Experience

Family Members' Experiences

A mix of excitement and apprehension.

Realization by non-caregiver family members of daily effects of injuries.

Reintegration challenges including:

- Resumption of co-parenting.
- Re-establishing family relationships.

Caregiver shoulders responsibility of medical-care oversight (monitors conditions; manages home-based medical and rehabilitative care).

Family members experience grief, resentment, guilt, anger and hopelessness as they all adjust to living with the consequences of severe injury.

Family members want their life back.

Once SPC Brown is home, he and his family face many challenges as they adjust to new roles and responsibilities. While they are happy to have everyone home, there also is a sense of trepidation as they continue this journey without ready backup available from hospital staff. While Mr. Brown has seen his son before his homecoming, and has kept current on his progress, he now witnesses the daily struggles his son faces in the foreseeable future. He and Mrs. Brown face coordination issues as they, for the first time in 22 months, jointly manage all responsibilities under one roof. Mrs. Brown juggles her role of primary caregiver to SPC Brown with re-establishing her parental relationship with her other sons and her spousal relationship with her

husband. The Browns' younger children, now 17 and 19, adjust to a new living arrangement and begin to understand fully the impact their brother's injuries will have on his life – and theirs.

Initially, Mrs. Brown is intimidated by some of the procedures she performs that previously was done by hospital staff. She is careful to make sure her son receives the right amount of each medication, at the right time, each day. She works with and encourages her son to complete rehabilitative therapies as they strive to continue recovery from TBI and PTSD. She monitors changes in her son's condition and symptoms and accompanies him to all medical appointments. She provides most of his daily living assistance. She, along with the rest of the family, experiences emotional challenges as it becomes clear they never will get their old life back and that this situation will require a life-long, enduring effort. Mrs. Brown experiences varying amounts of depression, compassion fatigue, and other emotional challenges associated with exposure to long-term trauma. How well she takes care of herself depends on how successful she is in her efforts to obtain VA-provided in-home Aid and Attendance, respite care, and responsive medical and rehabilitative care for her son.

Mr. Brown continues to work full time, be the primary parental point of contact for his two younger sons, and takes on the responsibility of modifying a bathroom in their home to make it easier for his son to bathe and to use the toilet and sink. Mr. Brown explores non-profit resources as needed to supplement government resources for his son's care and rehabilitation. Mr. Brown also ensures his younger sons are receiving the care and attention they need. Like Mrs. Brown, Mr. Brown's ability to take care of himself depends largely on how much red tape and bureaucracy he has to navigate to get the services and benefits that his son needs. As the male head of house, Mr. Brown finds it difficult to accept that he cannot fix this for his wife and family. He feels unable to take the time or money necessary to seek counseling.

Family Members' Experiences

Continues to work with, and be frustrated by, the VA to obtain grants/benefits earned by service member.

Home modification requires extensive personal time and expense to complete.

Further explores non-profit resources for service member's care.

Faces growing financial concerns as family caregiver continues to be unable to earn an income.

Works daily to help service member regain independent-living skills.

Seeks counseling as time and money permit.

SPC Brown's younger brothers, while relieved that their brother survived, also experience emotional challenges as their lives are overshadowed somewhat by his.

Several months after the Brown family has reunited at the family home, SPC Brown has made progress toward regaining some independent-living functions. Through continued speech, cognitive and physical therapy, he now is able, with great effort, to verbalize his thoughts and desires. He can stand, unattended, for short periods of time. He is learning coping methods for managing the loss of short-term memory capabilities. He also has made progress in relearning social-interaction skills that were destroyed when his brain was injured. Frustration accompanies these cognitive improvements as SPC Brown desires to progress faster toward restoring speaking, thinking and memory capabilities. SPC Brown also continues treatment to address emotional outbursts and agitation associated with PTSD, as well as ongoing prosthetic care and physical therapy to regain mobility.

Mr. and Mrs. Brown are encouraged with the improvements in their son's life skills and desire to continue rehabilitative therapies. They research new developments in treatments of TBI and private-care alternatives. They find making the transition from VA-provided care to private care will require a complex approval process and additional personal costs.

Specialist Brown

OIF Veteran, 25 years old, unable to live independently, working every day to recover.

Living at home with parents, frustrated by cognitive and mobility limitations.

With great effort, able to verbalize thoughts/desires and stand unattended for short periods of time.

Learning adaptive methods to address short-term memory deficits.

Receiving outpatient rehabilitative care for PTSD, TBI, and prosthetics care.

Desires to regain independence and self-sufficiency.

Concerned about long-term care, specifically, what will happen to him if he is unable to recover fully and his family becomes unable to provide in-home care?

SPC Brown's younger brothers graduated from high school and wish to attend college. As a result of Mrs. Brown's lost income and additional expenses associated with SPC Brown's care, limited funds are available to cover college expenses.

The Browns eventually settle into a somewhat routine, although strenuous, way of life. Their routine includes doggedly pursuing resources, therapies and medications to help their son regain independent living. They know the time may come when these rehabilitative efforts will be replaced with palliative efforts to ensure their son is stable and comfortable and safe from harm – but for now, they maintain hope that his condition will continue to improve.

Mr. and Mrs. Brown decide to take a short family recreational break away from caregiver responsibilities. They want to include their oldest son but decide it is in his best interest, and that of his younger brothers, to include him on a future trip after he has regained more mobility. As they investigate VA-provided respite care, they discover 24-hour care is available only in a VA-certified facility (e.g., a nursing home). An 8-hour in-home option is available. They are unwilling to place their son in a nursing home, so they select the in-home option and go to a local recreational attraction.

Mr. and Mrs. Brown face the reality that they may not always be able to provide the daily care their son requires. As they research long-term assisted-living care, they discover that cost implications restrict them to one option, a VA nursing home. They visit the Georgia War Veterans Nursing Home and find it geared toward the care of aged veterans with routine medical needs. They are very concerned about how their son might fare in that environment. With no other viable options, they are left to hope that day never comes.

Family Members

Parents and siblings living with severely injured OIF veteran, working every day to recover.

Encouraged by progress, desire to continue rehabilitative therapy as long as positive effects are obtainable.

Evaluating effectiveness and quality of rehabilitative care, researching all options.

Striving to meet emotional, educational and financial needs of all family members.

Have established a daily routine and desire an occasional break.

Concerned about long-term care alternatives, specifically, who will take care of their son if and when they no longer can care for him themselves?

At Home - Model of Support

By the time Mr. and Mrs. Brown live together again, they have spent almost 2 years living apart. They did whatever it took to provide the best care for their injured son, all while caring for their home and the needs of their other children. This journey took a toll on their financial, emotional and physical states. Military families are resilient, resourceful and hard-working. They do not want or need handouts, but they do need federal, state and local resources to help them rebuild their lives after this devastating experience. It is imperative that families do not become “out of sight, out of mind” when they go home. More specifically, there are four areas that require consistent attention.

First and foremost, high-quality medical and effective rehabilitative care must continue for the service member. Family members must know where to turn in the event they become dissatisfied with the quality of care. If the family desires to seek care at another facility, their FRC should work with them (as discussed previously) to identify the options and the cost of those options.

Secondly, income and insurance replacements (as discussed in the At Hospital section) must continue until such time that the service member’s daily living needs no longer prohibit his/her family caregiver from working. When the caregiver is able to return to work, provide vocational assistance and employment services as needed to increase employability and career opportunities. Manage the transition to ensure seamless insurance coverage.

Third, continue previously established supports such as respite care (as discussed in the At Hospital section) and timely access to quality individual and family counseling.

Continue active case management to:

- Administer/coordinate the previously developed community-integration plan – placing particular emphasis on: pending claims for VA and other federal (Social Security, Department of Labor, etc.) benefits, grants, compensation or services
- Complete efforts (if modifications still are incomplete) to establish an accessible home that meets the rehabilitative needs of the service member and the living needs for the rest of the family
- Facilitate connections to local community support resources

Lastly, provide alternatives to traditional VA nursing homes with transitional and residential housing designed to address the unique medical, rehabilitative and emotional needs of young, severely injured veterans.

Model of Support During Home-Based Care

- ✱ Continued family and patient-centered high-quality medical and rehabilitative care.
- ✱ Continued income and insurance replacements.
- ✱ Vocational assistance for caregiver.
- ✱ Continued access to individual and family counseling (**provide in home if necessary to accommodate family needs**).
- ✱ Provide in-home, overnight respite care.
- ✱ Provide long-term assisted living solutions that consider age, medical, rehabilitative and emotional needs of severely injured veterans.
- ✓ Continued proactive case management.

Other Family Composition Possibilities

This case scenario is a realistic possibility given that about half of all service members are single, 94 percent of those wounded in action are enlisted, and 55 percent are under the age of 25.¹⁶ There are, however, other families facing similar situations, whose individual support needs will vary based on their family composition, income, native language, location and other variables. Possibilities include:

- Single service member, no children, one surviving parent
- Married service member, no children, working spouse
- Married service member, with spouse and young children at home
- Single service member who is the only living parent of minor children
- Single or married service member with adult dependents
- Single or married service member with special-needs minor children
- Single or married service member whose caregiver does not speak English

The Model of Support describes a system of care that relies on proactive, hands-on family support to anticipate each **family's unique needs** while creating an environment that will enable and empower them to rebuild their lives.

¹⁶ <http://siadapp.dmdc.osd.mil/personnel/CASUALTY/OEFWIA.pdf> and <http://siadapp.dmdc.osd.mil/personnel/oif-wounded-total.pdf>

The Model of Support at a Glance

The diagram on the next page illustrates the Model of Support described on the previous pages and has color-coded symbols to denote which currently are provided, currently provided with room for improvement, and those that are not provided currently.

A MODEL OF FAMILY SUPPORT FROM INJURY, TO HOME, AND BEYOND

A MODEL OF FAMILY SUPPORT FROM INJURY, TO HOME, AND BEYOND			
INJURY	TRAVEL TO BEDSIDE	AT HOSPITAL	TRANSITION TO OUTPATIENT
<ul style="list-style-type: none"> ✓ Prompt Telephone Attention ☐ In Person Support/ Assistance Officer ☐ Notebook 	<ul style="list-style-type: none"> ✓ Pre-Arranged Travel From Home To Hospital 	<ul style="list-style-type: none"> ☐ Pre-Paid Lodging and Meals ☐ Communications Support ☐ Education Regarding Treatment Options ☐ Overall – One Point of Contact – Life Long Case Manager ☐ Emotional and Mental Health Support ☐ Assistance with Child Care (or Other Dependant Care) ☐ Financial Consideration for Daily Living Assistance Provided by Family Caregiver ✗ Replacement for Family Caregiver Loss of Income ✗ Replacement for Family Caregiver Loss of Medical/Dental/Life Insurance ☐ Legal Assistance for Establishing Guardianship and Other Legal Issues Related to Veteran Care ☐ Preparation for Pay and Benefits Changes Related to Changes in Active Duty Status ☐ Respite Care ☐ Recreational Opportunities ✓ Coordinated, Pre-Paid Move to Subsequent Facility or Home ☐ Assistance Obtaining VA Benefits, Compensation, and Grants 	<ul style="list-style-type: none"> ☐ Education Regarding Possible Emerging Medical Conditions and Treatment Options ✗ Private Sector Community Resource Coordinator for Unmet/Underserved Needs ✓ Coordinate Home Health Services ✗ Home Visit To Prepare Home and Family for Veteran Arrival ☐ Develop Community Integration Plan and Establish Local Connections
			AT HOME
			<ul style="list-style-type: none"> ☐ Continued Rehabilitative Therapy for Veteran ☐ Med. Appointment Transportation Assistance/Reimbursement ☐ Caregiver Vocational Assistance ✗ Long Term Care Tailored to Veteran Age, Medical, and Rehabilitative Needs

✓ = Currently provided
 ☐ = Currently provided, improvements suggested
 ✗ = Not currently provided

Part 2: Family Caregiver Perspectives

The most important building block to establishing the Model of Support was feedback from families who are living this experience. They know what would have helped them most during their journey as well as what is most needed now as they continue to rebuild their lives. The Quality of Life Foundation reviewed family member testimonies from congressional hearings on “Care of the Severely Wounded,” interviewed case managers and other service providers, and corresponded with dozens of families. Overwhelmingly, the comments reflected the themes identified on the following pages.

“Simply put, I felt alone. I felt as if I had to quit my job, pack up my family, and relocate to a different city entirely on my own.”

Spouse caregiver - San Antonio, Texas

Feeling Isolated and Unsupported

“The process was incredibly alienating, and I wanted to find out how other people coped with a similar circumstance.”

Spouse caregiver - Alabama

“I needed someone who had been through this to be a mentor for me – to help me understand that I will get through this.”

Parent caregiver - Florida

“I don’t have the time to research how to get help, how to provide the best therapy for my son – I need one place to go to – my tool box – with resources for whatever I, or my son, need. Take away the responsibility of researching the issues when someone out there already knows the answers. Make it easier for me to find those answers.”

Parent caregiver - Pensacola, Fla.

“I lived in a hotel room for 5 months . . . here was no personal family support, no spouse/caregiver support group in place.”

Spouse caregiver – Killeen, Texas

“It would be helpful to have a one-stop shop of all the grants that were available to us, not having to find them all myself. Also, a forum or sounding board to talk about benefits and grants.”

Spouse caregiver - Knoxville, Tenn.

“If there is any help that I have needed in regards to my mental health, I have had to find all on my own . . . and that is after I have just hit rock bottom.”

Spouse caregiver - Fort Wainwright, Alaska

“I am not sure if there are services to help care for his medical needs properly and how much will be put upon us to just deal with, as though his military service never occurred.”

Spouse caregiver - Fort Wainwright, Alaska

“I would love to be able to go to a caregiver’s conference or some kind of support group for family members, but don’t know if that exists in our rural area.”

Spouse caregiver - Grandview, Wash.

Financial Impacts

"I lost my job due to taking too much time off work to be with him."

Spouse caregiver – Loxahatchee, Fla.

"The loss of a second income by many families has increased the need for personnel to claim bankruptcy."

Spouse caregiver – Fort Sam Houston, Texas

"Out-of-pocket expenses for new clothes after surgery, transportation to hospital and therapy, and products for pain."

Spouse caregiver - Fort Leonard Wood, Mo.

"Financial impact high (i.e., depleted savings to meet expenses)."

Spouse caregiver - Round Lake, Ill.

"Job placement would be welcomed. I am degreed/educated and marketable, but assistance with an online teaching job would alleviate a huge burden from us."

Spouse caregiver - San Antonio, Texas

"We need reimbursement for loss of work and transportation expenses to the VA. The nearest VA with specialists is 2 hours each way. That is a half day loss of work and a lot of gas money - all of which we pay out of pocket with no reimbursement."

Spouse caregiver – Manchester, Conn.

"I spend \$35 round trip for one VA appointment; they reimburse me \$7."

TBI/PTSD wounded veteran - Victorville, Calif.

"Even though spouse provided non-medical attendance for over a year, only received 1 month of compensation due to being assigned. It took a long time to get TSGLI and almost two years to get Social Security disability payments."

Spouse caregiver - Knoxville, Tenn.

"We were making payments out of our pocket for travel expenses when he had out of town appointments and surgeries. Applying and receiving reimbursement for those expenses was often delayed . . . These expenses occurred when we weren't planning for them, and we had to use money set aside to cover bills. Then we would be late with our payments. I also had to turn down job offers to provide the constant care that was required for my husband after he was injured."

Spouse caregiver - Fort Wainwright, Alaska

"Financially, it has just about killed us."

Parent caregiver - Zanesville, Ohio

“We (children and caregiver) need to get away and do something fun – something that has nothing to do with the injuries or the recovery, an escape.”

Parent caregiver - Indiana

Family Stress and Fatigue

“Families are falling apart and crumbling. My husband and I separated; we dealt with our son’s injuries in different ways.”

Parent caregiver - Indiana

“I believe group therapy for my son (child of wounded service member) would be extremely beneficial. We were continuously told that there were no (mental-health) appointments available for my son. It took until December 2007 (3+ years after injury) for my son to finally be seen by a military provider.”

Spouse caregiver - San Antonio, Texas

“Our children have some support but still do not receive adequate mental-health care. The system is overloaded and cannot handle the number of kids that need help where we are. The qualified physicians are outnumbered by the children.”

Spouse caregiver - Fort Sam Houston, Texas

“We don’t have a life anymore.”

Parent caregiver - Massachusetts

“It’s very tough on the family. Anything that can be done to lessen the load on the family – we basically don’t have a life anymore.”

Parent caregiver - Maryland

“Our day is long. It typically begins at 5:00 a.m. and ends at midnight. It’s hard for us to identify what kind of help we need. I mean, there’s just not enough hours in the day. Jokingly, I’ve mentioned several times that what we really need is a personal assistant. We know that there are organizations or groups out there that offer support and assistance. However, we just don’t have time to research who and what’s available and to make contact with them. It would be wonderful to have a person who would know what resources are offered within the area a disabled soldier resides and possibly help establish contact with them.”

Parent caregiver - Maryland

“Continual counseling – both individual and marital – would have benefitted the family emotionally and helped ease the transition from military to civilian life.”

Spouse caregiver - Canton, Texas

*Bureaucracies Surrounding
Military and Veterans Affairs Pay
and Benefits and Transition Issues*

“All this time and effort and no one listens. How many times do you have to tell your story for something to happen?”

Parent caregiver - Pensacola, Fla.

“What we really need is someone to be absolutely honest with us regarding the retirement/benefits process. My concern is that we will fall through the cracks . . . because we forgot to fill out a single form.”

Spouse caregiver – Lafayette, Ala.

“I am very apprehensive on what to expect during the medical-board process that he is entering and what will happen to our family and the ability to provide for ourselves after his expected discharge from the service.”

Spouse caregiver – Fort Wainwright, Alaska

“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.”

Parent caregiver - Virginia

“Veterans and their families should be assigned case workers who visit with the veteran and family (at their home) on a monthly basis . . . the case worker should be fully trained in ALL benefits available to the veteran.”

Spouse caregiver – Loxahatchee, Fla.

“Homes are not usually wheelchair adapted at the time of discharge.”

Visiting Nurse – Navy Marine Corps Relief Society

“I work a part-time job to pay for respite care because I do not want to place my husband in a VA nursing home temporarily so I can get a break. My part-time work then also becomes my respite.”

Spouse caregiver – North Carolina

“The best way to provide family support is to start by providing quality care to the wounded service member.”

Spouse caregiver – Loxahatchee, Fla.

“Take care of my son’s needs, and most of my needs will be met.”

Parent caregiver - Pennsylvania

“Be honest with me about my son’s prognosis, but also leave room for some hope. Don’t tell me that there is absolutely no chance for recovery.”

Parent caregiver - Pensacola, Fla.

“We had to fight for three months to get my son referred to private care where he had the best chance for TBI rehabilitation – the VA must give these guys what they need, when they need it, at the beginning of their treatment.”

Parent caregiver - North Carolina

“Provide transitional housing for my son. He is highly functioning but cannot hold a job with the results of his TBI. Invest in him, and others like him, with transitional housing and vocational rehabilitation so they can eventually learn how to behave in a work environment and move towards living independently.”

Parent caregiver - Pensacola, Fla.

“We wanted our son to receive care at home, where our family could all be together and all be a part of his recovery. We had to fight to get care at (a private institution); they wanted us to stay within the VA system. That was not the best choice for our son and the rest of the family.”

Parent caregiver - Massachusetts

“Who will take care of my son when I am no longer able?”

Parent caregiver - Florida

Parent caregiver - Massachusetts

Parent caregiver - North Carolina

Parent caregiver - Indiana

*Access to Patient and
Family-Centered High
Quality Medical and
Rehabilitative Care for the
Service Member*

Part 3: Conclusion and Recommendations

As military families pay the price of freedom by trading in their once normal lives for a years-long response to their service members' catastrophic injuries, we, as a country, must shoulder our share of that cost by providing services, income and programs that are tailored to maximize the recovery for the service member and restore the quality of life for the whole family.

The Military Services Wounded Warrior Programs, the Veterans Affairs OIF/OEF and Federal Recovery Coordinator Programs, other federal resources and many non-profits are working diligently to deliver this much-needed support. Especially since 2007, rapid and drastic improvements have been implemented to serve the nation's wounded with dignity and respect. New initiatives appear regularly. Top DoD and VA officials routinely address conferences and the news media to inform the public of current offerings and pending improvements. They also routinely declare that while things are getting better, there is much more work to be done. The Quality of Life Foundation agrees with the assessment that more needs to be done, especially as it relates to supporting the severely wounded family.

Despite the best efforts of multiple military, VA and non-profit case managers, the months a family caregiver spends away from home to provide bedside care at a military or VA hospital often leads to financial peril and emotional and physical exhaustion. Then, often at a point when financial and emotional reserves are at their lowest, caregivers leave the safety net of 24-hour medical support and return home with their veteran to begin an exhausting phase of recovery, relying primarily on VA-provided benefits and compensation to meet the high demands associated with in-home care.

Nothing we do can erase the event that brought these families to this point. Nothing can change the fact that from this day forward, their lives will be markedly different. However, we can, and must, ensure that the supports to help these families survive injury, and rebuild quality lives, are easy to obtain, relevant to their needs, proactive and long-lasting.

"Knowing is not enough; we must apply. Willing is not enough; we must do."
Johann Wolfgang von Goethe, German playwright, poet, novelist, 1749-1832

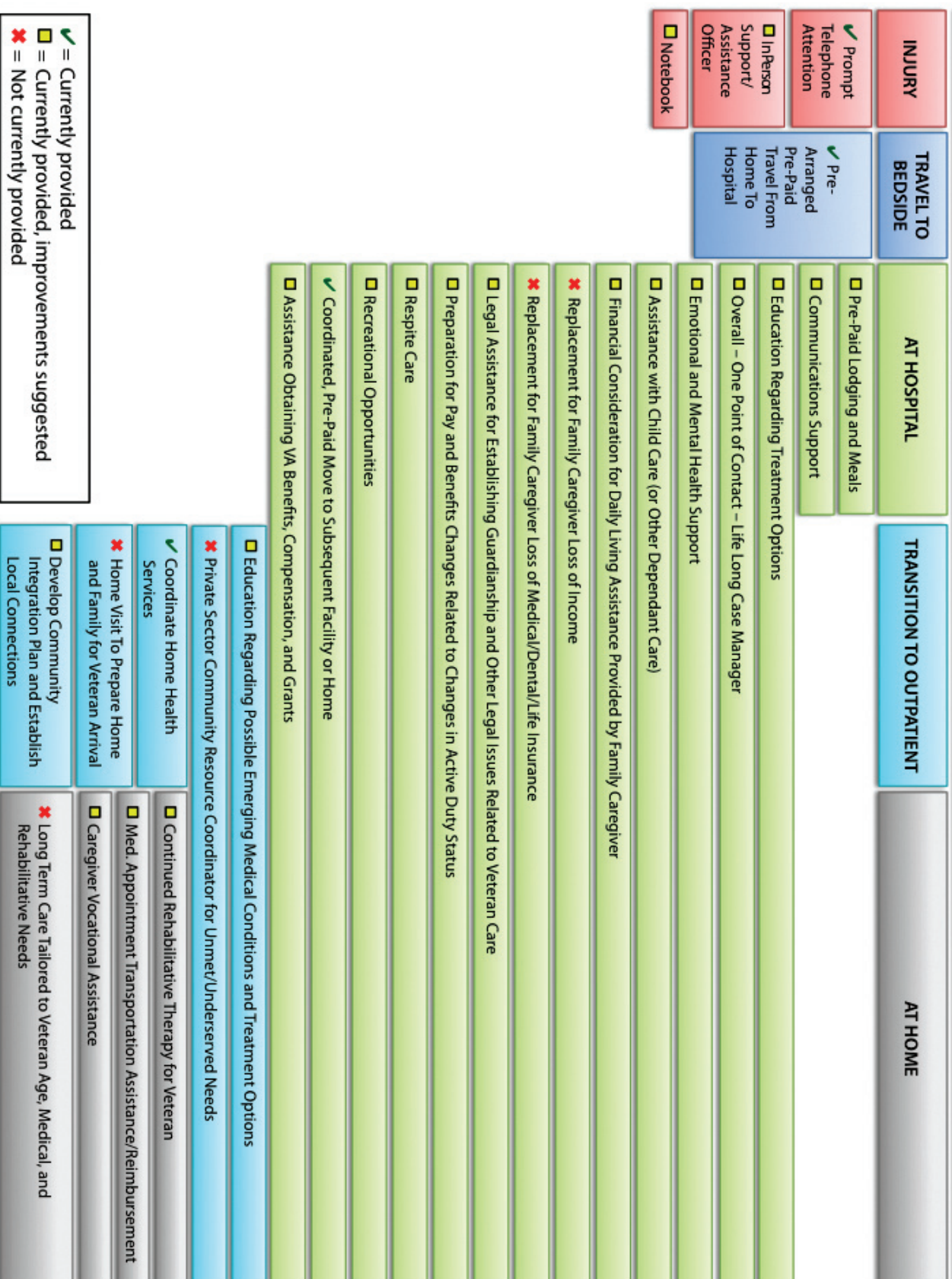
Four Guiding Principles

The Quality of Life Foundation identified four guiding principles to shape programs for these families.

- I. Ensure access to the highest-quality medical and rehabilitative care from injury to home to maximize service member recovery and independence.
- II. Prevent families from becoming financially strapped, emotionally drained, and physically exhausted while providing bedside care.
- III. Prepare the family and home environment for a successful transition home.
- IV. Support the family after transition home with quality of life services and rapid resolutions to emergency needs.

The chart on the following page illustrates opportunities to incorporate our four guiding principles across the full spectrum of family care. Detailed recommendations follow.

A MODEL OF FAMILY SUPPORT FROM INJURY, TO HOME, AND BEYOND

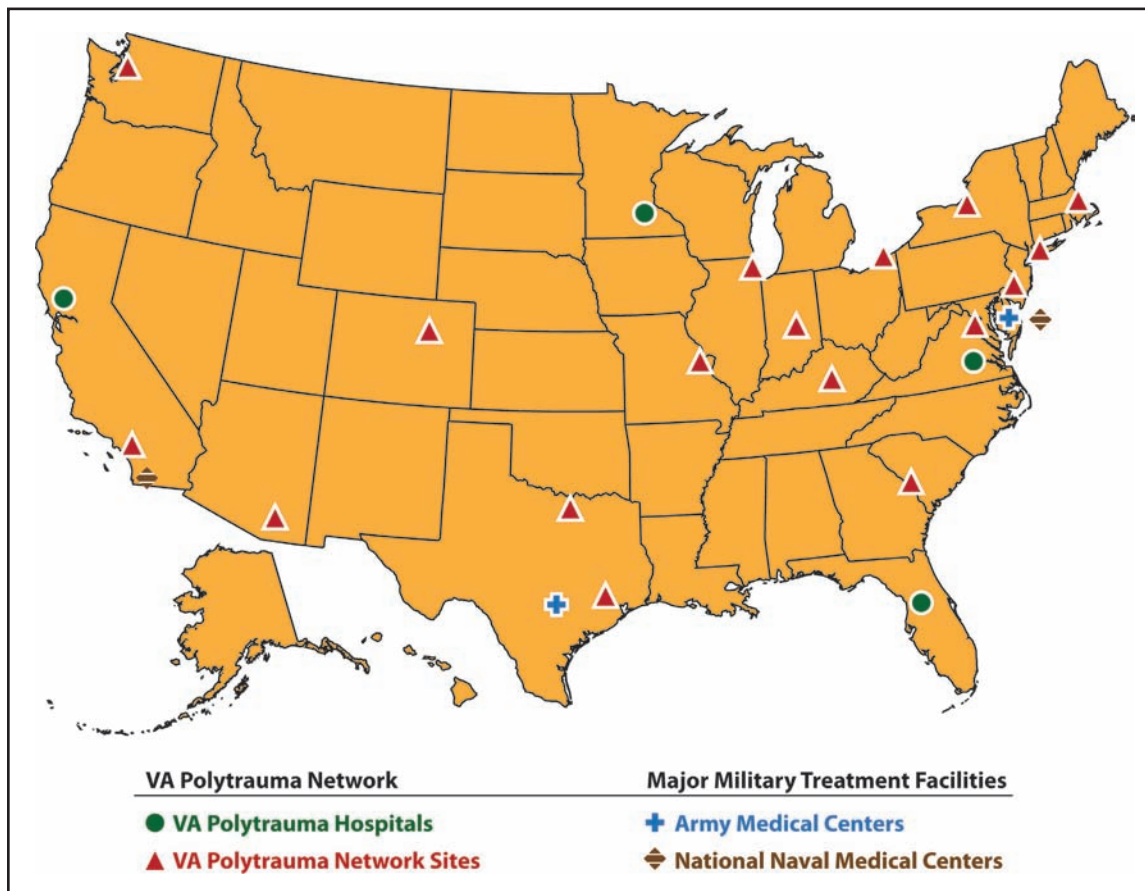


Guiding Principle 1

Ensure access to the highest-quality medical and rehabilitative care from injury to home to maximize service member recovery and independence.

1. Education Regarding Treatment Options

Military Treatment Facility (MTF) and/or Veterans Affairs (VA) Facility medical personnel educates family members regarding their service member's medical condition, prognosis and treatment plans. In general, these physicians steer service members to receive care at one of four MTFs or one of 21 VA Health Administration Polytrauma Facilities found on the map below.



While these sites all provide quality medical and rehabilitative care, sometimes the best option for a service member and his/her family is to receive care at a facility that either specializes in treatments for a particular injury, or is closer to his/her home, or both. It therefore is essential to:

- Educate families about the option to seek treatment from private-care facilities, the costs associated with that option, and how to get that option approved.

- Expediently facilitate transition to private care, if selected, while maximizing TRICARE or VA fee-based coverage.

2. Continue Rehabilitative Therapy for the Service Member/Veteran

Simply put, if the service member/veteran and the family want to continue rehabilitative therapy, and there is a reasonable expectation that it will benefit the veteran, support that effort. Do not base the decision to discontinue, or deny access to, rehabilitative therapies on cost management alone.

3. Education Regarding Emerging Medical Conditions and Treatment Options

These service members/veterans have complicated medical conditions that will change, positively or negatively, over time.

- Educate family members regarding conditions that might emerge and how to recognize and best respond to those emerging conditions. (For example, spasticity and tone-management effects related to Traumatic Brain Injury.)

Guiding Principle 2

Prevent families from becoming financially strapped, emotionally drained, and physically exhausted while they provide bedside care.

1. In-Person Support at Family Home after Notification of Injury

Currently, in-person assistance is required only in the tragic event of death of a service member. While families of severely injured service members who live on a military installation certainly receive in-person support from rear detachment personnel, those who do not (for example parents who live far from a military installation) typically are provided telephonic support and instructions.

- Recognizing the emotional trauma a family member experiences upon learning a loved one has been catastrophically injured, provide in-person guidance, answers to questions, and transportation assistance.

2. Notebook to Family Member Upon Notification of Injury

Currently, a “Welcome to Walter Reed” or similar handbook is provided to family members upon their arrival at the military hospital. It contains a guide to the hospital, contact information, sections for taking notes, and other valuable and informative sections.

- Revise current handbooks to include a section for families to reference before they leave their home to help them better prepare themselves and other family members for their absence. Provide notebook to family shortly after notification of injury, before they leave their home.

3. Prepaid Meals and Semi-Permanent Lodging

Currently, family member lodging usually is prepaid; the cost of meals, however, is reimbursed via a per diem method. Family caregivers forfeit lodging if they leave it vacant for overnight respite and must re-establish a new temporary residence upon return. If the family caregiver has been in the original lodging for any length of time, they probably have accumulated some comfort items to make their time there more bearable.

- Provide pre-loaded debit cards, or cash advances (values based on the per diem rate for a specified amount of time) to minimize out-of-pocket, reimbursable expenses.
- Allow family members to maintain lodging when away for brief respite absences.

4. Communication Support

Family members need to connect with and update friends and other family members during lengthy hospital stays. Caring Bridge, a non-profit organization, offers cost free Websites to families in crisis; other non-profits routinely disburse phone cards to help families stay in touch. Recognize that not all family members will know about, or have access to, these resources.

- Provide a monthly stipend to cover reasonable cell phone costs.
- Provide Internet-connected computers in hospital rooms to facilitate families' access to online communication capabilities.

5. Overall – Life Long Case Manager

Veterans Affairs assigns Federal Recovery Coordinators (FRCs) to severely injured service members identified as most likely to be separated from military service. The FRC coordinates the overall support in conjunction with Military Service Wounded Warrior and VA OIF/OEF Case Managers. FRCs also coordinate services from other federal, state and local government agencies and stay current on non-profit offerings. Outreach efforts began in September 2008 to assign FRCs to severely injured veterans who already have transitioned to community living. The current FRC-client ratio is 1:14.

- Maintain a low FRC-client ratio to ensure sufficient time to tailor services to each family's unique needs.
- Intensify outreach efforts to those families who already have transitioned to community living.

6. Preparation for Pay and Benefit Changes Related to Changes in Active Duty Status

Military Wounded Warrior Program and VA Case Managers explain military status changes to families; however, many times families are surprised when service member income changes, or an entitlement ends as a result of a military-status change. Current case manager-client ratios range from 1:15 to 1:79.

- Ensure case managers are fully trained and caseload is low enough, to enable case managers to prepare families for the effects changes to service member military status will have on income, benefits eligibility, Non-Medical Attendant orders, and other family support factors (e.g., being placed on the Temporary Disability Retirement List or assigned to a Warrior in Transition Unit).

7. Legal Assistance

Many family caregivers need legal assistance when they are required to assume guardianship for their severely injured service member. While some family members receive assistance from the Judge Advocate General (JAG) staff, JAG does not always have the resources to assist them; and some family members do not have access to them.

- Provide legal assistance to allow family caregiver to meet service member needs

8. Proactive Emotional and Mental-Health Support for Family Members

Family caregivers have opportunities to attend hospital support groups and consult with hospital chaplains. Some take advantage of counseling services provided by a non-profit called Give an Hour. Others with TRICARE insurance seek mental-health services from within that network. Recognize that some family members may not know about, or be eligible to receive, these resources.

- Create a network of mentors – carefully selected and fully trained people who have been through a similar experience and who can provide advice, guidance, empathy and understanding. Assign a mentor to family caregiver, if desired.
- Provide responsive and accessible counseling opportunities to family members who seek them. Maintain continuity of care.
- Minimize wait times for appointments.
- Recognizing that caregivers often do not seek emotional or mental-health support – ensure a case manager, a chaplain, or a mental-health professional proactively checks on their emotional well-being. Include family members at home.

9. Child (or Other Dependent) Care Assistance

Family caregivers sometimes must leave minor children, or other dependents, behind to provide bedside care to their service member. Some take advantage of the services provided by the National Association of Child Care Resource and Referral Agencies (NACCRRA) to help find subsidized care for their children; others rely on family members or friends; and some have no option other than to bring their children with them to the hospital. Those who have adult dependents must secure expensive adult day-care services in their absence.

- Provide a stipend to cover the cost of dependent care when that cost is a result of the family caregiver providing bedside care.
- Expand on-site child-care capacity to ensure family caregivers who must bring minor children to hospital have access.

10. Financial Consideration for Daily Living Assistance Provided by Family Caregiver

Family caregivers provide daily living assistance to their wounded service member at bedside during the inpatient phase and after transition home. When the service member is still active duty, family members receive reimbursements for expenses (lodging, travel, and meals) as long as they are on Non-Medical Attendant Orders. Family caregivers of those service members who have been discharged from the military are not eligible for this funding. There is currently no financial support provided to the family caregiver in consideration of the daily living assistance they provide at home for their veteran.

- Base expense reimbursement for hospital-based care on whether the family caregiver is providing daily living assistance to the service member or veteran - in effect, uncoupling the issue of financial support from active-duty status, unit assignment, or other factors unrelated to caregiving.
- In the case of home-based care, provide financial support equal to what the Veterans Affairs Health Administration would pay to a commercial home health agency to provide the same level of personal care services. Consideration might be given to conditioning eligibility for such payments on a certification process.

11. Hold the Family Caregiver Harmless from Loss of Employment

Many family caregivers who spend months away from their jobs to provide bedside care to their service member wind up losing their jobs, and their employer-sponsored health, dental and life insurance. Their pre-injury financial obligations and insurance needs, however, do not stop. The result in many cases is financial destitution.

- Replace forfeited income and insurance coverage until the caregiver is able to resume employment. Adjust replacement income, if needed, to account for financial support received by the caregiver for providing daily living assistance.

12. Respite and Recreation

Family caregivers have opportunities to participate in short-term recreational events sponsored by the hospitals and non-profits. For longer-term respite requiring travel (e.g., a brief trip home), family caregivers rely on non-profits (i.e., Fisher House or Air Compassion) or their own finances to fund transportation expenses.

- Prepay travel expenses and retain caregiver lodging for periodic (i.e., bi-monthly) extended (i.e., not to exceed 7 days) respite.

Guiding Principle 3

Prepare the family and home environment for a successful transition home.

1. Assistance to Obtain Maximum VA Benefits, Compensation and Grants

VA Case Managers explain available benefits to family members and help them with the application processes. Disability compensation is calculated based on a VA- determined disability rating. Some families receive lower-than-expected disability ratings (and thus lower compensation) and experience delays in receiving other benefits/compensations/grants.

- Ensure service member/veteran income is sufficient to cover reasonably expected costs associated with the treatment of, and living assistance required due to, his/her catastrophic injuries.
- Ensure applications for benefits required for a successful transition home are submitted, processed and approved before the service member arrives home. These include Aid and Attendance, Specially Adapted Housing Grant, Automobile Adaption Grant, and Disability and Special Monthly Compensation.

◇ Remove VA Home Modifications rule that restricts grant to cover no more than 50 percent of the total modification cost.

◇ Increase VA Home Modification Grant amounts from current maximums of \$14,000 for non-veteran owned homes (i.e., a parent-owned home) and \$60,000 for veteran-owned homes to an amount more closely tied to actual costs of the modifications.

2. Private-Sector Community Resource Coordinator (CRC)

Military Services Wounded Warrior Program and VA Case Managers quickly resolve issues with benefits and services within their own systems. They also reach out to other government agencies to meet family needs. When existing government supports cannot resolve an issue, they refer families to non-profit and other community resources. These federal employees are restricted from soliciting non-government resources and are not funded to provide direct financial assistance to meet emergency needs.

- Develop a private-sector supplement to the case-management services provided by the Military Service Wounded Warrior Programs, the VA OIF/OEF Program, and the VA Federal Recovery Coordinator Program. The key components include:
 - ◊ Proactive, well-trained, family advocates working within the veterans' communities prior to their transition home and providing continued support until the veteran and family opt out.
 - ◊ Quality of Life-focused, family-tailored supports with emphasis on community connections and independent living.
 - ◊ Structured coordination with, and cycle of feedback to, Military and VA Case Managers regarding supports provided.
 - ◊ Rapid access to privately raised funds to meet emergency or underserved needs.

3. Home Visit to Prepare Home and Family for Veteran Arrival

The FRC coordinates the overall effort of hospital staff and VA and Military Service Wounded Warrior Case Managers to prepare the family for the transition home and community integration. This is all done in person at the hospital, or over the phone – but does not include a home visit.

- Conduct a home visit to ensure the best understanding of the family environment and the pre-homecoming needs. This visit could be completed by either the FRC, the private-sector CRC, or both.

4. Pre-Homecoming Counseling

Reintegration challenges are a fact of life for every family when their service member returns from deployment. How much more complicated will these challenges be when compounded by severe, life-altering physical wounds?

- Develop tailored “pre-homecoming” counseling to help prepare families for challenges inherent with severe disabilities. Provide that counseling, accompanied by follow-on counsel, as needed.

5. Community-Integration Plan and Established Local Connections

The FRC develops a transition plan and a “Life Map” for the family that incorporates goals for the entire family. Part of this plan is to connect the family with local community resources. Currently, the FRC handles all community coordination via phone or e-mail.

- Conduct a community visit to meet with local resources (i.e., Veterans Service Organization (VSO) chapters, faith-based organizations, hospitals, and state and

local government organizations) and establish positive connections. Introduce family members to contacts. This visit may be done best by the private-sector CRC given the regulatory limitations of federal employees.

6. Facilitated Access to Non-Profit Resources

Military Services Wounded Warrior Program and VA Case Managers have established relationships with many existing non-profit organizations and refer families to them when there is a need that cannot be met with government-provided resources. In addition, the Department of Defense developed the America Supports You Program to highlight non-profit groups wishing to support military members and their families. One feature of this program is a Website that provides links to sites of non-profit organizations, listed alphabetically and categorized by the people they want to help (e.g. Help for the Wounded). Families who are referred to this Website can spend hours reviewing each site to find an organization that can help.

- Provide an automated way to input family-specific information (i.e., branch of service, city and state location, assistance requested) to match families more quickly and accurately with non-profits that may be of assistance. Provide this tool to government and non-profit case managers, as well as family caregivers.
- Develop and implement a vetting process to ensure only functioning, reliable organizations are listed on America Supports You Website.
- Host a workshop of non-profits who desire to collaborate to identify best practices for meeting the most urgent needs of severely injured families.

Guiding Principle 4

Support the family after transition home with quality of life services and rapid resolutions to emergency needs.

1. Transportation Assistance/Reimbursement for Medical Appointments

Family members often travel great distances to accompany their veteran to appointments at VA hospitals or MTFs. Reimbursements often do not cover the actual travel expenses (lodging, meals, gas, etc). Some families rely on assistance from Veterans Service Organizations or other non-profit organizations to fund these travel expenses; others rely on their own finances.

- When the veteran is directed to receive their care at a VA hospital or MTF, and that facility is more than 30 miles away, reimburse actual travel expenses. For trips requiring air transportation, prepay travel expenses.

2. Caregiver Vocational Assistance

When family members are able to return to work, they may need vocational training and employment services to secure a job that is conducive to their caregiver responsi-

bilities. Some may need extended daytime attendant service for the veteran to enable the family caregiver to return to work.

- Extend service member VA Vocational Rehab and Employment Services to family caregivers.
- Extend allowable daytime attendant services to facilitate family caregiver employment (may require more than current 8-hour maximum). Veteran's disability compensation will be used to pay applicable charges.

3. Respite and Recreation

The VA provides two types of respite services; one is in home care for up to 8 hours per day; the other is 24-hour residential care in a VA-certified facility (e.g., a VA nursing home). The annual maximum is 30 calendar days. TRICARE also provides up to 8-hour in-home, daytime care. Families who desire overnight, in-home respite care for extended absences (i.e., for a vacation or caregiver hospital stay) must bear the cost for that service.

- Provide in-home 24-hour/day respite care for up to 30 calendar days per year.

4. Long-Term Care Tailored to Veteran Age, Medical and Rehabilitative Needs

Family caregivers may not always be able to provide in-home care to their veteran. Existing VA nursing homes generally are designed for the care of the aged and chronically ill and may not have the expertise in providing care related to Traumatic Brain Injury, PTSD, severe burns, paralysis, blindness and other catastrophic injuries.

- Develop VA assisted-living facilities designed to meet the unique medical, rehabilitative, emotional and recreational needs of severely injured young veterans.

Conclusion

By implementing the prescribed recommendations, we can improve an arduous situation. To assert that we can return lives to normal would not address accurately the realities faced by these families. The fact is, regardless of the supports we put in place, they face a life-long challenge. This is an undeniable cost of war.

*“Never Leave a
Fallen Comrade”*

We can, however, reduce those challenges through improvements to existing resources and development of new resources. In so doing, we come closer to fulfilling our country's vows to “Never Leave a Fallen Comrade” and “To Care for Him Who Shall Have Borne the Battle.”

But who should implement which recommendations? Supporting our wounded service members requires a collaborative effort of the federal government, the private sector, and the community. Department of Defense and Veterans Affairs Administration leadership

must continue to press for legislative changes and increased funding for their support programs, and Congress must support those requests. Leaders of non-profit organizations should collaborate to identify best practices regarding the delivery of community-based supports to severely wounded families. In addition, individuals can donate their time and money to help meet unmet and underserved needs.

What are the costs associated with these recommendations, and further, will the resulting improvements justify that cost? Perhaps we should consider those costs in the same manner that every soldier, airmen, Marine, or sailor did when they voluntarily joined the military and signed a blank check offering all to defend and secure our country: When they said, “Whatever the personal cost to me and my family, I am willing to pay it for my country.” Did the soldier who was ripped apart by an IED during a convoy calculate a cost justification before departing on that dangerous mission? Did the Marine perform a cost-benefit analysis before he began a rooftop search and wound up with a Traumatic Brain Injury from a sniper’s bullet? They did not weigh the costs; they simply did their duty and made good on their promise. We, as a nation, need to make good on our promise to them.

“Young men and women who step forward and join this country’s armed services must have confidence that they and their families will be taken care of if something happens on the battlefield. As I’ve said before, after the wars themselves, we have no higher priority.”

Secretary of Defense Robert M. Gates, Colorado Springs, Colo., May 13, 2008

Next Steps for Quality of Life Foundation

The Quality of Life Foundation wrote this report to highlight the difficult challenges faced by care-giving family members and provide an outline for action to improve support to the whole family unit. Clearly, these recommendations require partnerships between government agencies, non-profit organizations, concerned individuals and businesses – collaborating to integrate families back into communities.

As we move forward, the Quality of Life Foundation will focus on supports that prepare the family for a successful transition home and that provide practical assistance after they make the transition home. We will: 1) take a leadership role to develop a national Private Sector Community Resource Coordinator Program; 2) facilitate family access to existing non-profit resources; and 3) establish a fund to meet urgent, underserved, or unmet family needs.

It is our hope that our specific actions, in combination with the actions of other organizational leaders, will result in another step forward in the steady progress our country is making to provide the very best in responsive supports to severely injured service members and their families.

If you would like to learn more about, or participate in, the Quality of Life Foundation's efforts, please visit our Website at WWW.QOLFOUNDATION.ORG, call us at (703) 496-9050, or e-mail us at INFO@QOLFOUNDATION.ORG.

APPENDICES

Appendix A: Government Resources

To supplement information obtained via family-member feedback, we researched government-funded resources to learn what services exist to support them. We found a large number of government programs, staffed with dedicated personnel who are working determinedly to meet the needs of the severely wounded family, with the services their programs contain. Most government agencies provide some program to support severely wounded service members; the Social Security Administration (SSA), the Department of Labor (DOL), the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Department of Housing and Urban Development (HUD) are some of the more well-known. For example, SSA provides disability payments to severely wounded veterans who are 100 percent disabled and unable to work. The DOL has the Veterans Employment and Training Service (VETS) that provides workshops for veterans and their spouses to increase their marketability. VETS also provides vocational rehabilitation to veterans who are able to participate. The SAMHSA is developing programs to provide mental-health services to meet the unique needs of severely wounded service members. HUD has special programs for veterans at risk of losing their homes. These are just a few examples of the types of programs most federal agencies have for the severely wounded veteran.

In addition, state governments administer benefits and assistance programs for severely wounded veterans. They vary from state to state, but most provide, subsidized: hunting and fishing licenses; state park admittance; state taxes; vehicle registration and licenses; and college tuition. Some state-level VA agencies have robust Wounded Warrior Programs, connecting wounded veterans with community supports, while others primarily administer the federally-funded services.

This section provides a synopsis of the programs and services provided by the Department of Defense (DoD) and the Department of Veterans Affairs (VA), the two primary service providers to wounded warrior families. As they are reviewed, readers should note accessibility by non-dependent caregivers (i.e., parents) and availability of supports during the At-Home phase of care.

Department of Defense Programs

Military Services Wounded Warrior Programs

The Army, Navy, Marine Corps and Air Force each have their own Wounded Warrior program. While each has branch-specific features, they operate with similar goals. Those goals are to provide case-management services to the wounded service members and their families and to address all issues that arise as a result of the injury. These case managers are trained thoroughly in military and VA benefits, other federal benefits for the disabled, and non-governmental supports. The case managers begin their work upon the service member's arrival at the Military Treatment Facility (MTF) and continue providing services after they are discharged home. Case managers focus on advocacy for the service member but also work to support the family as best they can.

Advocacy for the service member includes:

- Resolving pay issues.
- Processing service awards.
- Explaining different discharge scenarios and their pay and benefits impacts.
- Explaining how to navigate Medical and Physical Evaluation Boards.
- Helping service members continue on active duty (if desired and possible).
- Explaining what to expect with transition to VA.
- Coordinating with VA staff to ensure seamless transition to veteran status.
- Explaining other federal program benefits (Social Security, DOL, etc.).

Support for the family includes:

- Coordinating living and travel arrangements during service member hospital stay.
- Explaining different discharge scenarios and their pay and benefits impacts.
- Providing referrals to other support agencies as needed for urgent needs.

The following provides specifics pertaining to each military service program:

Army Wounded Warrior (AW2) Program

Initially established in April 2004, the AW2 Program serves about 2,700 soldiers and their families with over 80 Soldier Family Management Specialists (SFMSs) located throughout the country at major MTFs, VA Medical Centers (VAMCs) and Army installations.¹ That calculates to about 34 families per SFMS, or 54 hours per year per family.² AW2 maintains a Website with program information, links to other resources, updates on Wounded Warrior issues, and a blog. They also host an annual symposium to obtain input from clients and staff members on improving their services.

Marine 4 Life (M4L) Program

The Marine for Life Program falls under the command of the Marine Corps Wounded Warrior Regiment, which was established in April 2007. The regiment has a battalion on each coast and maintains a single data base and tracking system for all wounded and ill Marines, regardless of the severity of the illness or injury. The regiment currently follows about 9,500 combat-wounded Marines who have left the Marine Corps since 9/11 and about 500 active duty service members as they progress through their recovery and transition.³

M4L operates a 24-hour call center and a Website that contains news, information and links related to specific injuries, benefits, non-profit organizations and the recovery process. In addition, the regiment has a charitable organizations coordinator who keeps a current network of non-profit organizations that stand ready to assist wounded warrior families.

1 <http://www.army.mil/-news/2008/04/30/8862-army-wounded-warrior-program-honors-four-years-of-service>

2 Assumes a full time SFMS works 230 days per year (260 less 10 vacation days, 10 federal holidays, six sick days, and four training days)

3 http://sempermax.com/doc/2008_Navy_Surgeon_Generals_Award1.doc

Air Force Wounded Warrior (AFWW) Program

The AFWW program (formerly known as the Air Force Palace HART program) serves 317 service members (21 active duty and 296 retired or discharged) with four full-time equivalent (FTE) personnel.⁴ If each FTE is assigned equal numbers of families, each would be responsible for supporting 79 families. That calculates to about 23 hours per family per year.⁵ The service member is tracked monthly for five years after separation or retirement. For those who cannot return to active duty but are able to work, AFWW strives to secure Special Air Force federal civilian employment placement.

Navy Safe Harbor Program

The Navy Safe Harbor program provides personalized support and assistance to 262 severely injured sailors and their families (157 active duty, 105 retired) with 17 full-time equivalent (FTE) case managers.⁶ If each FTE is assigned equal numbers of families, each would be responsible for supporting 15 families. That calculates to about 119 hours per family per year.⁷ Case managers contact active-duty sailors at least once a month. However, contact is based on needs and in most cases is more frequent. Navy Safe Harbor focuses on successful community integration and assists in that process, then follows up with an annual letter that provides program updates, contact information, and a reaffirmation of their commitment. If the family responds to that letter with a support need, the case manager works to find resources to fill that need.

Military Services Wounded Warrior Programs Recap

Programs provide logistics support to the families during their stay at the hospital; guide families through complex military and transition issues to obtain the best long-term benefits for the service member; and refer to outside resources to meet uncovered/unexpected needs. Support is most intense during acute medical treatment but continues throughout transition to VA and after military separation for as long as the family needs.

⁴ Department of the Air Force correspondence to Quality of Life Foundation, dated Aug. 29, 2008

⁵ Assumes a full time staffer works 230 days per year (260 less 10 vacation days, 10 federal holidays, six sick days, and four training days)

⁶ Department of the Navy correspondence to Quality of Life Foundation, dated Sept. 8, 2008

⁷ Assumes a full time staffer works 230 days per year (260 less 10 vacation days, 10 federal holidays, six sick days, and four training days)

In addition to the AW2 Program, the Army has Soldier and Family Assistance Centers (SFAC) at large medical centers and Army installations.

Army Soldier and Family Assistance Centers

There are seven major Army Medical Centers and 33 Army installations with SFACs to assist families as they provide bedside care to their wounded service member. These centers are staffed to answer family members' questions and address their concerns as they relate to the following types of issues:

- Entitlement and benefits counseling.
- Military personnel services, such as ID cards.
- Transition and employment assistance.
- Social services to include financial counseling, stress management, translator coordination and Exceptional Family Member Program services.
- Travel pay for family members on Invitational Travel Orders (ITO).
- Substance abuse information and referral for family members.
- Coordination of legal and pastoral services.
- Lodging resources for family caregivers.
- Child-care referrals.

Soldier and Family Assistance Center Recap

Provides logistical and practical support while family is caring for service member at an Army Medical Center bedside.

Service Family Support Centers

Almost all military installations have a Family Support Center that provides a broad range of services that may include: individual and family counseling; personal financial counseling; and spouse employment services. These centers serve all military service members and their families. They provide a ready resource for those who have access to a military installation.

Military OneSource Resources

Military OneSource is a DoD-sponsored initiative that provides a wide range of support services to all military families via a Website, call center, and short-term counseling services. Military OneSource has a segment of their call-center staff and Website dedicated to serving the severely injured and their families. In addition, families of severely wounded service members can obtain the MOS short-term counseling services.

The Wounded Warrior Resource Center (WWRC) and Website

The WWRC is a subsection of the Military OneSource call center located in Arlington, Va. The WWRC offers an additional avenue of assistance staffed by specially trained consultants who identify the appropriate “warm hand-off” either to a military service or federal agency with authority to resolve the matter. The resource center consultant maintains communication with the caller until the issue or concern is resolved.

WWRC consultants help explain available benefits; identify resources; and obtain short-term counseling, information and support. The call center is open 24 hours a day, seven days a week with a toll-free number. Consultants give personal, ongoing assistance related to financial resources; education; training; job placement; VA benefits and entitlements; home, transportation, and workplace accommodations; family counseling; and personal mobility and functioning.

The WWRC also has a section on the MOS Website full of resource articles and links to helpful organizations. Examples of the articles include: *“Becoming a Caregiver for Your Adult Son or Daughter”* and *“Entering the Workforce When Your Spouse Has Been Severely Injured.”*

WWRC Call Center and Website Recap

24/7/365 call center that offers telephonic support and problem resolution to wounded warriors and their families. Staff provides referrals to short-term counseling services and to existing support agencies as necessary to meet family needs. The Website contains helpful articles regarding issues for the severely wounded family and links to helpful organizations.

The WWRC/American Legion Heroes to Hometown Program

The Heroes to Hometowns (H2H) program was developed by the Department of Defense and works in partnership with the American Legion (AL) to help severely wounded Global War on Terrorism veterans successfully return to civilian lives. H2H focuses on preparing the community to receive the wounded family before they return home by proactively establishing networks at the national, state and local levels to identify community resources to meet the extraordinary needs of returning families.

Each state has paid staff to coordinate their local programs in their communities. In theory, American Legion posts across the country already have formed Hero to Hometown committees that are waiting to welcome wounded warriors home.

When a post learns of a wounded warrior coming home, their Hero to Hometown Committee will assemble a “Hero Transition Team” (HTT) to review information on the returning family’s needs, requirements and expectations and make plans for gathering resources to meet those needs. Immediate needs may include temporary and/or permanent housing; assistance in adapting a home or vehicle; help finding jobs and education opportunities; and transportation aid for hospital visits. HTTs are encouraged to conduct major community events prior to the homecoming to raise local awareness and support and to hold a welcome-home event for the wounded service member and their family. By conducting a welcome-home event, following up with individualized care, and being a constant source of support, the AL members prepare the service member and their family for a successful reintegration. As of November 2008, assistance has been provided to more than 400 families in 37 states and two territories.⁸

WWRC/American Legion Heroes to Hometown Program Recap

Community-based program designed to meet family-specific needs as they return to their community. Program relies on volunteer and community involvement.

⁸ Estimate based on information from prepared statement of the Honorable David S.C. Chu, Undersecretary of Defense (Personnel and Readiness) before the House Armed Services Committee hearing on “Challenges and Obstacles Wounded and Injured Service Members Face During Recovery,” March 8, 2007, and statement from Edward Diaz, H2H Program Coordinator, Nov. 24, 2008.

Military OneSource Counseling Services

Military OneSource offers in-person and telephonic short-term, non-medical counseling services to all active-duty, Reserve and National Guard members and their families.

When a family member is in need of counseling, they can call a toll-free number to speak with a consultant about that need. The consultant conducts a brief assessment and then provides a referral for in-person counseling to a licensed professional counselor in the caller's local community. If the family member is unable to attend in-person counseling sessions (due to their location or other circumstances), the consultant provides a referral for a telephonic consultation.

Military OneSource counseling services are designed to address short-term issues. Each eligible family member may receive up to six sessions, per issue, per counselor, at no cost. If counseling is needed for additional issues, the family member must call again to obtain another referral for a different counselor. For issues that require long-term counseling, the family member must obtain care through other avenues (i.e., TRICARE Providers or MTFs).

Mental-Health Care via Military Family Life Consultant (MFLC) Program

This program (similar to, but separate from, Military OneSource) provides up to six sessions of no-cost counseling to family members of active-duty service members (those who have not yet separated from the military). Family members call a toll-free number to be referred to a provider. The program is designed to address short-term issues and employs over 250 consultants. MFLCs can be deployed to provide on-site services or may provide telephonic counseling as appropriate.

Military OneSource and MFLC Program Short-Term Counseling Services Recap

Family members receive up to six no-cost counseling sessions for each issue. Sessions either are face-to-face, or telephonic, depending on family member needs. These services are not an option for: non-dependent family members, (i.e., a parent caregiver); non-active duty family members, (i.e., a spouse of a medically-discharged service member); or persons with issues requiring long-term counseling.

Military Health Care System Family Support Initiatives

The Military Health Care System provides medical and mental-health care to all active-duty service members and their dependents at MTFs, civilian hospitals, and physicians' offices via the TRICARE Management Activity (TMA).

Medical Health Care for Family Members via TRICARE

Dependent family members of severely injured service members typically qualify for TRICARE. This insurance provides medical care via the rules and regulations established by TMA. It is similar to the coverage they had when their service member was active duty but now requires an annual enrollment fee for the coverage. Family members who are not dependents of the service member (i.e., a parent caregiver) are not eligible for TRICARE.

Mental-Health Care for Family Members via TRICARE

Dependents may call a toll-free number, or go online to the TRICARE Website, to receive a list of TRICARE-approved mental health providers from which they can receive no-cost counseling for up to eight sessions. If the family member requires more than eight sessions, the counselor and the family member's primary-care physician must coordinate a referral to authorize additional services. Family members who are not dependents of the service member (i.e., a parent caregiver) are not eligible for this benefit.

Medical and Mental Health Care for Family Members Recap

Dependent family members (i.e., spouses and children) have access to medical care and short and long-term counseling. Access to care is dependent on provider availability and the ability of the family member to leave caregiver responsibilities to attend appointments.

Case Management for Wounded Warriors via TRICARE Regional Contractors

The United States is divided into three TRICARE Regions, with a regional contractor for each: Healthnet Federal Services, Humana Military Healthcare Services, and TriWest Health Care Alliance. Each contractor has a case management program designed to meet the unique support needs of severely wounded families; highlights of those programs follow:

Healthnet Federal Services Warrior Care Support Program

- Consistent, knowledgeable support and personal assistance.
- Appointment scheduling, coordination of timely referrals for doctor and therapy visits, and coordination of services with military or VA.
- Assistance with benefit coverage including changes that occur with military status.
- Coordination of mental health care as needed.

Humana Military Healthcare Services Warrior Navigation and Assistance Program

- Coordination with military treatment facilities, community-based health-care organizations and the VA.
- Clinical case managers to assess, plan, monitor and evaluate options and services to meet the warrior's health care needs.
- Nurse navigators to provide information and coordination in situations which do not require case management.

Triwest Health Care Alliance Complex Health Care Case Wounded Warrior Program

- Individualized case-management services for both internal care coordination services and coordination with military treatment facilities, community-based health-care organizations and the VA.
- On-line resource directory.
- Financial support to community-based programs that serve wounded service members and their families.

Department of Veterans Affairs Programs

The mission of the Department of Veterans Affairs (VA) is “To care for him who shall have borne the battle and for his widow and his orphans.” They strive to restore disabled veterans to the greatest extent possible and improve the quality of their lives. The VA also supports family members with the following programs and benefits.

Veterans Affairs Health Administration

Polytrauma Case Management and Family Support

Polytrauma care is for severely wounded service members with injuries to more than one physical region or organ system, which results in physical, cognitive, psychological or psychosocial impairments and function disability. Because these service members require daily oversight by their family caregivers, the VA encourages their involvement throughout the rehabilitation process and supports them with case management and logistical, clinical and emotional resources for needs related to service-connected injuries. The VA also works with community organizations and businesses to coordinate lodging, transportation, meals and recreational activities for families.

The polytrauma team educates families regarding their service member’s medical conditions and actively engages family members in treatment decisions, including discharge planning. Family members are invited to join therapy sessions prior to discharge so that they can learn how to help the patient be as independent as possible in the home. Prior to discharge, family members may be scheduled to stay with the patient in a family training apartment to allow the caregiver to experience what the return home may be like while rehabilitation staff and nursing still are available to answer questions, address unexpected problems, and provide emotional support. The VA also offers educational sessions and family counseling to help families cope with adjustment issues following injury.

Polytrauma Case Management Recap

Polytrauma case managers coordinate whole care, update appropriate military services personnel on service members’ condition, and refer family members for in-house emotional support and external resources for logistic and financial support needs. Family members receive training, education and emotional support in preparation for discharge.

Federal Recovery Coordinator Program

The Federal Recovery Coordinator Program (FRCP) was initiated in May 2008 and complements existing Military Services Wounded Warrior and VA programs to support severely injured service members and their families by providing a process to identify and integrate care and services, from the onset of injury to community reintegration.

Eligible severely wounded service members are assigned a Federal Recovery Coordinator (FRC) shortly after their arrival at the MTF. The FRC coordinates federal health-care teams and private community resources to achieve the goals identified in a Federal Individual Recovery Plan (FIRP). FRCs are a family's overall, lifetime point of contact.

Currently FRCs are located at Walter Reed Army Medical Center, Washington D.C.; National Naval Medical Center in Bethesda, Md; Brooke Army Medical Center in San Antonio, Texas; and the National Naval Medical Center in San Diego, Calif.

As of September 2008, 119 patients were in the program staffed by eight full-time employees.⁹ Efforts are underway to identify the severely wounded who already have made the transition to communities and may be in need of this program's services.

Federal Recovery Program Recap

A VA/DoD Joint Case Management program designed to provide many of the same services as the Military Services Wounded Warrior Programs but only for the most severely injured. The program provides a Federal Recovery Coordinator (FRC) to oversee all service member care and family support. The FRC develops a "Life Map" with rehabilitation and community-integration goals for the whole family and provides lifelong coordination to adapt the plan as needed. Holistic focus attempts to link service members and their families with the tools and resources required to maximize their quality of life.

⁹ Stars and Stripes, Pacific Edition, Oct. 2, 2008, "Catastrophically Wounded Gain Life Long Advocates," Tom Philpott

Vet Centers

The Vet Centers are community-based outreach centers designed to serve discharged combat veterans and their family members. The goal of the Vet Center program is to provide a broad range of counseling, outreach and referral services to eligible veterans to help them make a satisfying post-war readjustment to civilian life. If needed, staff will meet with family members outside of normal office hours to accommodate their needs. Vet Centers serve the wounded warrior family by providing no-cost counseling to them for any service-connected issue. While Vet Centers are supposed to be for veterans and their family members, exceptions may be made for active-duty service members who are in the process of being discharged (based on the availability of counselors). There are 232 Vet Centers located across the United States. Family members can find their nearest Vet Center by visiting the Website, WWW.VETCENTER.VA.GOV.

Vet Center Recap

No-cost, in-person counseling is available for family members of severely wounded veterans (not for active-duty families) at 232 Vet Centers across the country. Access to care is dependent on family member proximity to the Vet Center, counselor availability, and the caregiver's ability to leave responsibilities to attend counseling.

Veterans Affairs Benefits Administration

The Veterans Affairs Benefits Administration provides many programs, grants and disability payments that indirectly support the families of the severely wounded by providing a source of income and offsets to expenses related to living with disabilities. The amounts vary based on a number of factors, including the VA-assigned disability rating, number of dependents, and other factors. Most require an application process and have complex eligibility requirements. Summary information on these programs is provided below.

Traumatic Servicemembers' Group Life Insurance (TSGLI)

Traumatic Servicemembers' Group Life Insurance (TSGLI) is traumatic-injury protection that provides payment to any member of the uniformed services who suffers a traumatic injury that results in certain severe losses. The complete listing of eligible injuries, and resulting payments, is quite lengthy, but payments range from \$25,000 to \$100,000 for severe wounds including loss of limb, blindness, severe burns, and traumatic brain injuries. The intent of the TSGLI payment is to help service members and their families cover the unexpected loss of income and additional expenses that come with lengthy medical care associated with traumatic injuries. About 4,400 people (2,550 with Traumatic Brain Injury) had received TSGLI payments when a July 2008 revision to the program's eligibility criteria added another 1,230 recipients.¹⁰ The VA offers free financial counseling for recipients of TSGLI; however, many families do not attend.

TSGLI Recap

TSGLI is a one-time lump-sum payment to severely injured service members, between \$25,000 and \$100,000, intended to help offset unexpected loss of income and additional expenses that come with long-term medical care.

¹⁰ http://www.airforcetimes.com/news/2008/07/military_traumaticinjury_insurance_071708w/

Disability Compensation

Monthly disability compensation is paid to severely wounded service members based on their service-connected disability and number of dependents. The table below provides the basic monthly amounts for disability compensation. Veterans with certain severe disabilities may be eligible for additional special monthly compensation. These benefits are not subject to federal or state income tax.

2009 Disability Compensation Rates for Veterans Without Dependents

Veteran's Disability Rating	Monthly Rate Paid to Veterans
10 %	\$123
20 %	\$243
30 %	\$376
40 %	\$541
50 %	\$770
60 %	\$974
70 %	\$1,228
80 %	\$1,427
90 %	\$1,604
100 %	\$2,673

VA Disability Compensation Recap

A monthly payment based on severity of disability that is subject to offsets by income received for military disability or military severance pay.

The following provides summary information on the most common grants and payments that may benefit severely wounded service members and their families. Each has its own eligibility criteria and application process. None is automatic; amounts often are based on complex formulas including total income, other grants awarded, disability rating, and other factors.

Specially Adapted Housing Grants

Severely injured service members may be entitled to a grant to help build a new specially adapted house, to adapt a home they already own, or buy a house and modify it to meet their disability-related requirements.

Service members who have blindness in both eyes or the loss of use of both hands are eligible for up to \$12,000 for necessary adaptations to their home, toward purchasing a new accessible home, or for adaptations to a family member's home in which they will reside. We will refer to this as a Level 1 Grant.

Service members who have lost both legs or both arms (above the elbow) or are blind and have lost one leg, or otherwise are wheelchair bound, are eligible for up to \$60,000 toward not more than 50 percent of the cost of building, buying or adapting existing homes or reducing indebtedness on a currently owned home that is being adapted. We will refer to this as a Level 2 Grant.

Veterans who are residing temporarily in a home owned by another family member (i.e., a parent or sibling) may use up to \$2,000 of the Level 1 Grant (or up to \$14,000 of the Level 2 Grant) to adapt the family member's home to meet his/her special needs.

While the VA has averaged about 1,000 adaptive housing grant applications per year during the past 10 years, as of January 2008 more than 4,600 applications had been received in response to an outreach VA made to inform veterans of this benefit. Of those, about 3,900 veterans were determined eligible and more than 200 grants awarded.¹¹

To apply for a Specially Adapted Housing Grant, the veteran must submit an application to determine eligibility. If the veteran is deemed eligible, a local SAHG staff member will contact the veteran and set up an appointment to come to the home and determine what types of adaptations are needed and whether the home will accommodate those changes. If the home is deemed adaptable, the SAHG staff member will coordinate the necessary work with a VA-approved contractor. While appeals and subsequent waivers may result in larger grants, the amount of the SAHG is not supposed to cover more than 50 percent of the cost of the adaptation nor exceed \$60,000.

¹¹ VA news release – Jan. 4, 2008, “New VA Rules for Specially Adapted Housing Grants Program Aids Most Seriously Injured”

Automobile Adaption Assistance

Severely injured service members who have lost the use of one or both feet, of both hands or have impaired vision may be eligible for a one-time payment of up to \$11,000 toward the purchase of an adaptive automobile. The grant is paid directly to the seller of the automobile.

The severely injured service member also may qualify for a grant to cover adaptive equipment such as power steering, power brakes, power window lifts, power seats, and special equipment necessary to assist the eligible person in and out of the vehicle.

Adaptive-equipment grants may be paid more than once as long as the total of the grants does not exceed \$11,000. Grants may be paid either to the seller or the veteran.

Annual Clothing Allowance

Severely wounded service members with prosthetic or orthopedic appliance or skin conditions that need medications that ruin clothing may apply for an annual clothing allowance. If qualified, a veteran can receive a yearly allowance for reimbursement of \$677.

Aid and Attendance

Severely wounded service members who require the aid of another person to perform personal functions required in everyday living may be eligible to receive an additional payment to help cover the cost of the Aid and Attendance. The amounts are dependent on a variety of factors such as net worth, income and disability rating.

Special Monthly Compensation

The VA will pay additional Special Monthly Compensation (SMC) to a veteran who needs Aid and Attendance for daily life activities because of the loss, or loss of use, of specific organs or extremities including:

- Loss, or loss of use, of a hand or foot.
- Immobility of a joint or paralysis.
- Loss of sight of an eye (having only light perception).
- Loss, or loss of use, of a reproductive organ.
- Complete loss, or loss of use, of both buttocks.
- Deafness of both ears (having absence of air and bone conduction).
- Inability to communicate by speech.
- Loss of a percentage of tissue from a single breast, or both breasts, from mastectomy or radiation treatment.

The award amounts range from \$97 to \$7,070 per month. The calculation of SMC is quite complex and is dependent on the level of attendance required, the number of dependents, and the category of loss.

Long-Term Care Services

VA offers a variety of long-term care services. Such services include adult day health care; inpatient or outpatient respite care; inpatient or outpatient geriatric evaluation and management; hospice and palliative care; and home-based primary care. Veterans receiving these services may be subject to a co-pay. The co-pay is based on each veteran's financial situation and is determined upon application for extended care services and will range from \$0 to \$97 a day. Inpatient respite care is provided at VA nursing homes; outpatient respite care is provided at the veteran's home for up to 6 hours each day. Outpatient overnight care is not an option.

Miscellaneous VA Grants and Payments Recap

There are numerous benefits available to severely wounded service members. All have unique application processes and eligibility requirements and are dependent on a variety of factors including service member disability rating, total income, and number of dependents. While family members may benefit from these payments and services, the effort to determine eligibility, complete applications and waiting time is burdensome.

Summary

There is no shortage of government programs designed to support the severely wounded family. However, there is a shortage in the effectiveness of these programs as it relates to meeting the family support needs when and where they exist (especially for non-dependent family caregivers). It also is important to note that there is no shortage in the efforts and determination of the staff who administer these programs and services; however, they can only do what they are allowed to do within the confines of their program.

Some programs have been quite successful in delivering support, where and when needed. This is especially true during the initial notification of injury, travel to bedside, and the inpatient phase during acute medical care. The military services do an outstanding job getting family members to their service member's bedside in a timely and cost-free manner. DoD hospitals provide top-notch, life-saving acute medical care; case managers from the various Military Services Wounded Warrior Programs conduct repeated outreach at the hospitals to show support and provide information families need. And temporary lodging usually is available for family caregivers. Unfortunately, support diminishes greatly as the family makes the transition home and the caregiver assumes primary care responsibilities.

A common thread found among family support resources for the transition and at-home phases of the Model of Support is that they are reactive in nature, waiting for the families to find them. Once found, many are mired in bureaucratic systems that require mountains of paperwork and long processing times to receive an answer on whether the support will be obtained.

In addition, many programs sound good in theory but in reality are understaffed or underfunded to meet the support needs of all eligible families. For example, the VA Federal Recovery Coordinator Program, which assigns a life-long case manager (a Federal Recovery Coordinator, or FRC) to families of severely injured service members, is a great program designed to help meet short and long-term needs of the whole family. As of September 2008, this program had eight staff members to serve and 119 families. While this is a good start, there are many families who already have transitioned that are not yet enrolled into this program. In addition, the FRCs face the same challenge as other federally funded case managers in that they do not have ready access to funds to meet immediate needs and are restricted in the role they can play to solicit assistance from non-governmental agencies to meet short-term, emergent needs.

Military Service Wounded Warrior Program case managers also follow the service member for life. Their challenge, similar to the FRC, is they are limited in their ability to help with issues outside of those that can be solved with military/government resources (i.e., pay issues, medical board issues, etc.) because they do not have funding to provide other direct services to the families.

For example, if a case manager does a contact call to check on a family and the family member tells the case manager that he/she is having trouble coming up with a portion of the cost for a home modification – short of making sure the service member is getting all

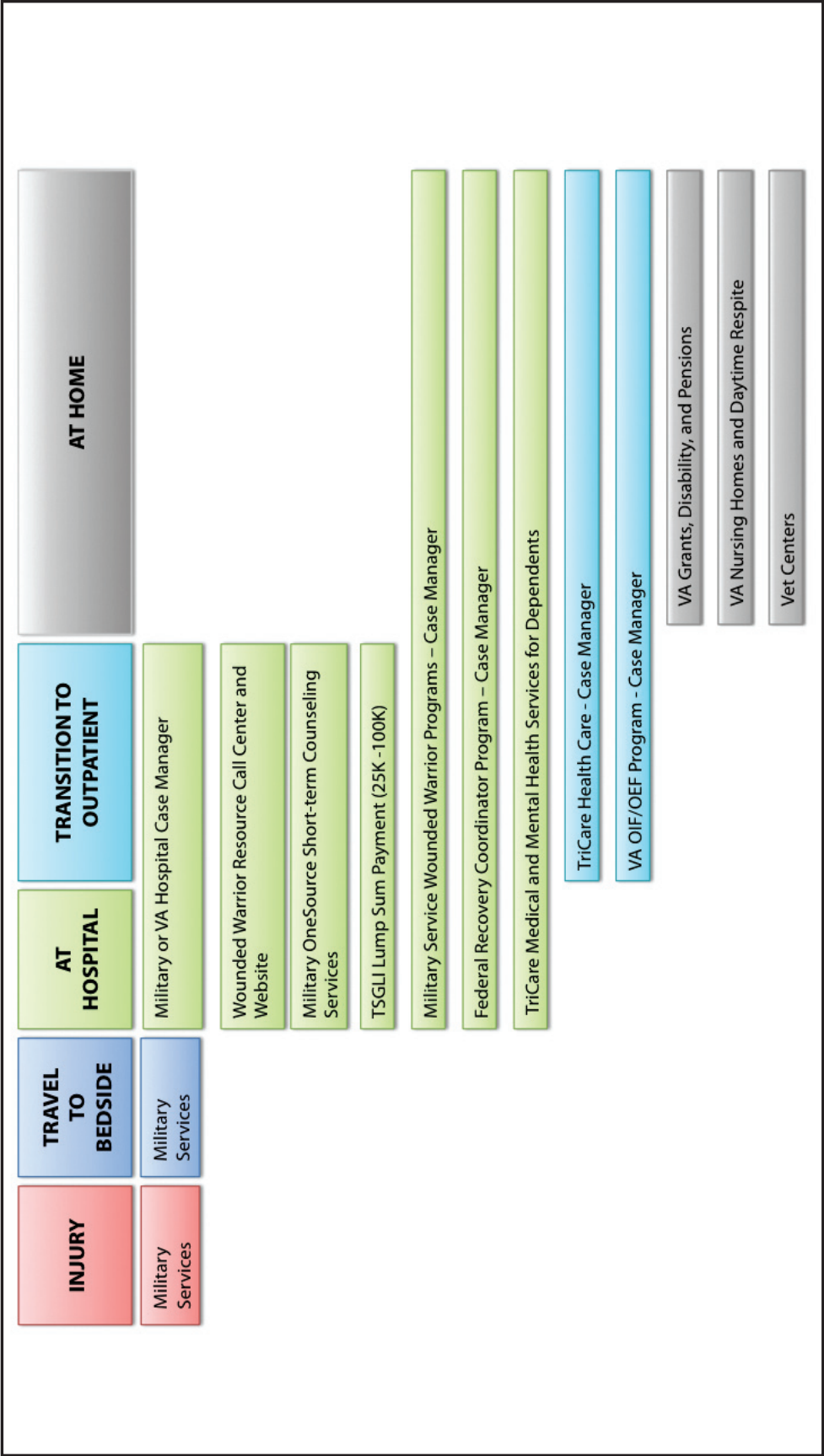
to which he/she is entitled from the service, the VA, and Social Security, the case manager has no tool with which to help. Instead, the case manager will refer the family to another organization (perhaps a non-profit or a Veterans Service Organization) to seek help. The case manager even may contact that organization on behalf of the family, but as a federal employee is not actually allowed to ask for assistance. Understandably, this scenario leaves both the case manager and the family frustrated. Case managers work diligently to find and coordinate access to resources and their efforts often are heroic. However, the resolutions for the families' struggles often lie outside the resources the case managers have.

Here are a few other examples of benefits that are provided but fall short of meeting the unique needs of this population:

- When a caregiver loses his/her job after an extended absence to care for the service member, there currently is no replacement for that lost income or for lost benefits. Instead it is assumed that the TSGLI payment, along with the service member's Social Security and VA disability and benefits payments, will cover those losses.
- In-home respite-care resources available through the VA are only for 6 to 8 hours of daytime care. Overnight care is available only if the family is willing to place their service member in a nursing home.
- Housing-modification grants are restricted to cover no more than 50 percent of the cost of the modification – with a ceiling of \$14,000 for homes that are not owned by the service member and a ceiling of \$60,000 for homes that are owned by the service member.
- Long-term care options and existing nursing homes often are designed around the needs of chronically ill and aged veterans and not young to middle-aged severely injured veterans.

Government-funded resources provide many families valuable support. But we need government-funded resources that are designed to meet the support needs of all wounded families and not just those lucky enough to participate in a pilot program, live in a particular area, or are able to navigate the VA eligibility and application process. A resource, by definition, is “something that is a source of help. . . a capacity that is drawn on in time of need.” Families should not have to struggle to obtain the resources they need to recover from the impact of their loved one's severe injuries.

The following chart places the government resources discussed earlier along the spectrum of the Model of Support and illustrates that 1) severely wounded veterans have numerous case managers who work to coordinate military and VA benefits, manage service member health care, and coordinate transition from active duty to veteran; 2) family caregivers have access to TRICARE medical and mental-health care - if they are dependents; and 3) severely wounded families are almost completely dependent on VA-administered income, grants and programs to meet their support needs once they return home.



The VA is funded to meet *veterans' needs*; the administration is not funded, and in some cases, not legislatively permitted, to provide services to the family members taking care of the veteran. Does it make sense, then, that families are so heavily dependent on the VA for the supports they need to restore and maintain quality of life?

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Appendix B: Non-Profit Resources

Families sometimes turn to non-profit and veterans services organizations, and military associations (NPOs, VSOs, MAs), for resources they are unable to obtain through their Military Service Wounded Warrior Programs, the VA, or other government-funded agencies. Many of these organizations also provide outreach programs at VA and military hospitals, and through their community chapters, to provide support to wounded warriors and their families. These families seek non-profit support at various times during their journey, from injury notification, through inpatient status, and after discharge.

While there are hundreds of NPOs (both military-oriented and those which serve a broader population) that provide services, financial grants and other supports to military families, we focused our analysis on the 143 that were listed under the category “Help for the Wounded” on the Department of Defense Website, America Supports You (ASY).¹ ASY was launched in 2004 to highlight citizen support for the military and connect service members and their families with NPOs that want to support them. The ASY Website is not an all-inclusive list of every NPO which assists the wounded. However, it does provide a significant representation of them, and families often are referred to this network when existing government supports are not able to respond rapidly to their needs.

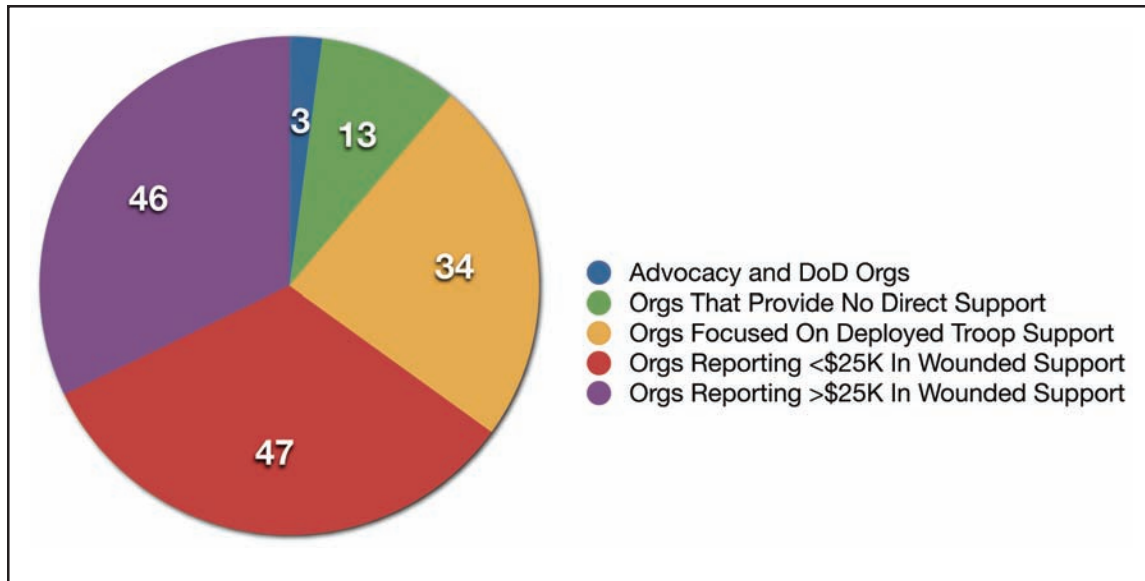
A family member seeking non-profit assistance using this avenue initially sees something very similar to the illustration on the following page, an alphabetic listing of organizations that have registered as a non-profit which helps the wounded. Because many organizations serve only specific regions (e.g., Tennessee) and clientele (e.g., Marines), or offer only limited resources (e.g., scholarships), caregivers can spend hours clicking on each link to find an organization that provides the kind of assistance they need, where they need it. The Quality of Life Foundation visited each Website, attempted to contact each organization either by phone or e-mail, and reviewed available IRS tax returns (most were from fiscal 2006) to learn more about this subset of resources. The following summarizes what we found.

¹ <http://www.americasupportsyoudmil>

America Supports You Homefront Groups

Adopt a Soldier Now	Grateful American Coin, Inc	Operation Life Transformed	The 4E Network, a NJ Non Profit Corporation
Air Compassion for Veterans	Helping our Heroes Foundation	Operation Military Embrace	The 9-11 Help America Foundation
American Freedom Foundation	Hero Hugs	Operation Second Chance	The Aleethia Foundation
American Legion	Hire Heroes USA	Operation Stars and Stripes	The Gene Vance Jr. Foundation for Cat. Inj. War Veterans
American Soldier Foundation	Homes for Our Troops	Operation Support Our Troops Illinois	The Greer Foundation
Angels'n Camouflage	Hope Coming Ministries	Operation: Quiet Comfort	The Hugs Project
Angels of Mercy	Hope for the Warriors	Operation: S.A.M.	The Mental Health Self-Assessment Program
Armed Forces Foundation	Hugs from Home	Our Military Kids	The Military Spouse Pinnacle Foundation
Army Emergency Relief	Injured Marine Semper Fi Fund	Pentagon Federal Credit Union Foundation	The Soldiers Project
Azalea Charities Air for Wounded Soldiers	Intrepid Fallen Heroes Fund	PFC Geoffrey Morris Memorial Foundation	The Soldiers', Sailors', Marines', Coast Guard, and Airmen Club
Back in the Saddle Bit by Bit (BITS)	Keystone Soldiers	Pilots for Christ, International	The Thank You Foundation
Blue Star Mothers Chapter Five	Lakeshore Foundation — Lima Foxtrot Program	Post War Military Family Needs	True to the Red, White, and Blue
Blue Star Mothers of America, Inc.	Landstuhl Hospital Care Project	Project TLC: Serving Those Who Serve	U. S. Troop Care Package
Blue Star Riders	Lost and Found, Inc.	Project Victory	U. S. Troops Support Foundation
Boatsie's Boxes	Marine For Life	Purple Heart	U. S. Wounded Soldiers
Bob Woodruff Foundation	Marine Parents	Rebuilding Together	United States Entertainment Force, Inc.
Bryan McDonough Military Heroes Foundation	Marine Parent's	Road 2 Recovery	United We Serve
Building Homes for Heroes	Mikes Guardian Eagle Foundation	Salute Military Golf Association	USA Cares
Captain Scott Corwin Foundation	Military Aid, Inc.	Salute Our Services	USO of Metropolitan Washington
CaringBridge	Military Child Education Coalition	Sentinels of Freedom Scholarship Foundation	USO World
Caring for Troops	Military Heroes Fund	Serving Those Who Serve	Vacation for Veterans
Central Illinois Proud Families of Marines	Military Ministry	Sew Much Comfort	Vet Dogs
Comfort for America's Uniformed Services	Military, Veteran, and Family Asst Foundation	Silver Star Families of America	Veteran Love and Appreciation Fund
Coming Home Project	Mothers of Military Support	Sock Monkey Ministries, Inc	Veterans Airlift Command
Defenders of Freedom	Music for Troops	Soldier's Angels	Veterans' Families United Foundation
Disabled Sports USA	National Homeland Defense Foundation	Southeastern Guide Dogs, Inc.	Veterans Outreach Center, Inc.
Eagle's Watch Foundation	National Military Family Association	South Florida Veterans Multi-Purpose Center	Veteran to Veteran
Enable America	National Rehab & Rediscovery Foundation	Still Serving Veterans	Warrior Foundation
Fallen Heroes Foundation	National Veterans Foundation	Strikeouts for Troops	Watering Seeds Organization
Family and Friends for Freedom Fund	Navy-Marine Corps Relief Society	Support Our Soldiers America	Wounded EOD Warrior
Fisher House	North Carolina Heroes' Fund, Inc	Tee it Up for The Troops	Wounded Heroes Foundation
Flags Across the Nation	Operation Family Fund	Tennessee Marine Family	Wounded Warrior Project
Freedom Calls	Operation First Response	Tennessee's Helping Hearts	Yellow Ribbon America
Freedom is Not Free	Operation Forever Free	Terry Farrell Firefighters Scholarship Fund	Yellow Ribbon Fund
Give 2 the Troops	Operation Helping HEAL	Thanks USA	
Give an Hour	Operation Homefront		
Golfers For Freedom	Operation Hope		
	Operation Interdependence		

First, we learned which organizations provide what types of services to which clientele. We also found that many would like to learn more about the services other non-profits provide and are interested in working collaboratively to develop a full spectrum of support for wounded warrior families. We learned that some non-profits had ceased operations due to lack of funding or other organizational issues; that some serve only a small, local clientele; while others were focused on providing services for a specific military service. More than 30 focused on sending care packages to deployed troops or military hospitals. And ultimately, we discovered 46 that provided large scale programs for the wounded and their families.



The preceding breakdown is not to say that only 46 of the 143 listed provide meaningful support – on the contrary, all that still are operating provide valuable support to those they have chosen to serve. Rather, the breakdown simply looks at these organizations through the eyes of someone who is facing an unmet financial, emotional or practical support need and is searching for an organization that can provide direct assistance.

For example, while the advocacy and DoD organizations listed provide great support to wounded families with legislative advances, clearing military and VA related issues (especially helpful with pay issues), and providing referrals to other agencies, they are not funded to provide direct financial support.

Similarly, the 34 organizations that focus on supporting deployed troops and their families back home also provide very beneficial services. In fiscal 2006, these organizations reported over \$50 million in programs that boosted the morale of deployed troops, enhanced educational programs for military children, provided scholarships to military dependents, and provided emergency financial assistance to families of deployed troops. (See breakdown on the next page.) While some of those programs may have benefitted families of the wounded, based on the Website and Form 990 information, less than 1 percent was identifiable as “wounded support.”

Program Expenses Focused on Deployed Troop and Family Support

\$40,000,000	By USO to benefit deployed service members everywhere
\$ 4,770,000	Education programs to benefit all military children
\$ 3,506,000	Scholarships to benefit all military dependents
\$ 1,387,000	General financial assistance to families of deployed troops
\$ 730,000	Care packages to deployed troops (some to hospitals)
\$ 97,000	Family support services to all Marine families
\$ 35,000	Retreats for families who have completed deployment
<u>\$50,525,000</u>	

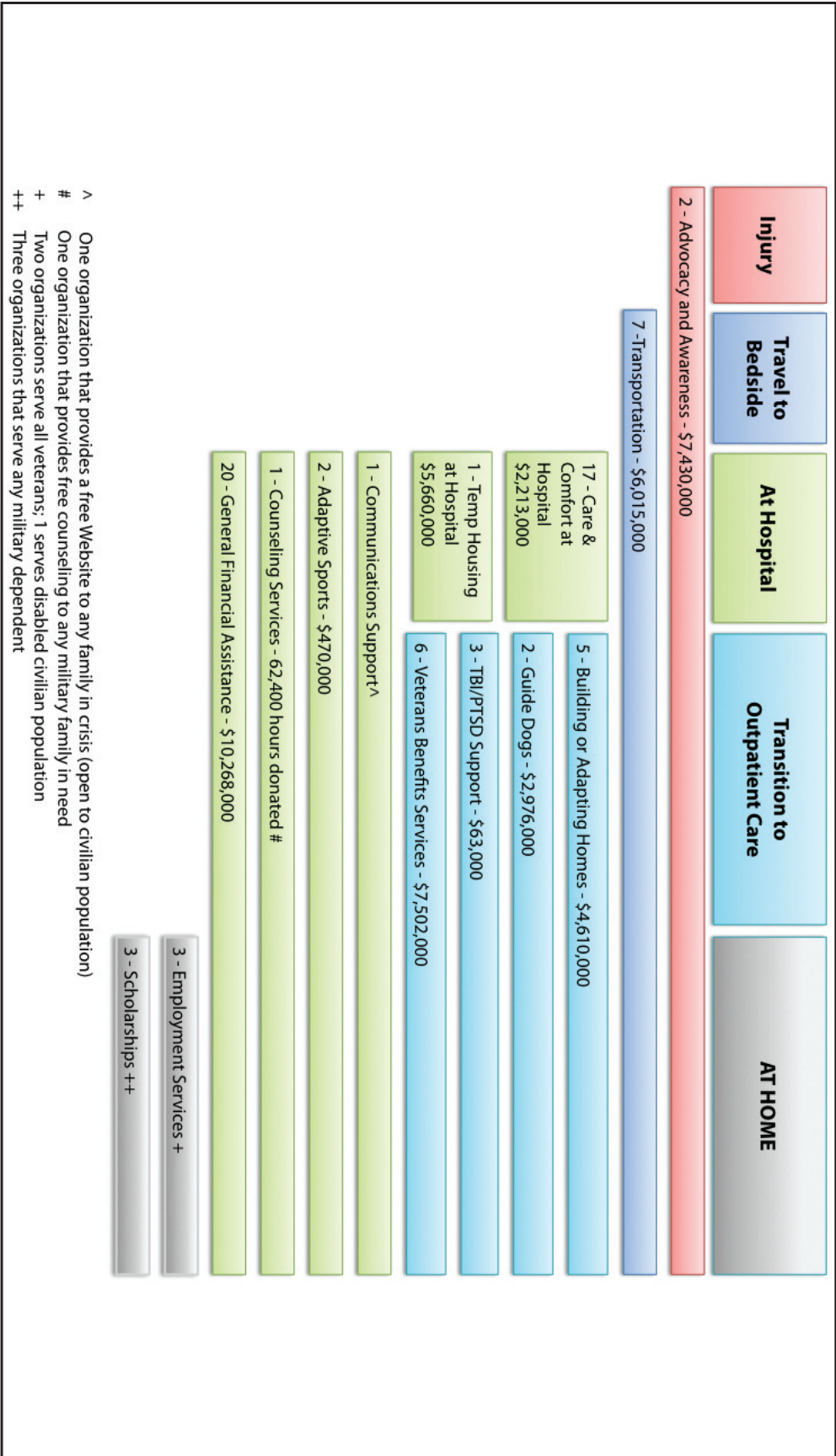
The 47 non-profits identified as “Reporting Less Than 25K in Wounded Support” also provided valuable support to their clients. Collectively, for fiscal 2006, they reported \$42,500 in program expenses that specifically supported wounded service members and their families, and \$277,300 in program expenses that supported a broader population of military and veterans (not exclusively for wounded service members). However, given their limited funds designated to wounded support, their capacity to assist a high number of wounded families is limited.

And finally, based on fiscal 2006 IRS Form 990s filed by the 46 non-profits identified as “Reporting More than \$25K in Wounded Support,” close to \$45 million was spent to provide support directly to wounded service members and their families; \$27 million was spent to provide support to a broader population of military and veterans; and \$12 million was spent to provide support open to the civilian population. Those broader programs may have included support for the wounded; however, expenses were not reported in a way that allowed us to make that determination. The chart on the next page provides expenses by category of support:

Support Category	Funds for Programs Specifically for Wounded Warriors and families	Funds for Programs Open to a Broad Population of Military and/or Veterans	Funds for Programs Open to the Civilian Population	TOTALS
Adaptive Sports	470,000	n/a	1,580,000	2,050,000
Advocacy/Awareness	7,430,000	n/a	n/a	7,430,000
Building/Adapting Homes	4,610,000	n/a	n/a	4,610,000
Care and Comfort at Hospitals	2,213,000	n/a	n/a	2,213,000
Communications Support	n/a	n/a	2,029,000	2,029,000
Employment Services	371,000	155,000	610,000	1,136,000
General Financial Assistance	10,268,000	22,004,000	n/a	32,272,000
Guide Dogs	n/a	2,976,000	440,000	3,416,000
Scholarships	n/a	765,000	n/a	765,000
TBI Support	63,000	n/a	7,146,000	7,209,000
Temporary Housing	5,660,000	n/a	n/a	5,660,000
Training Caregivers/Counselors	194,000	n/a	n/a	194,000
Transportation	6,015,000	502,000	n/a	6,517,000
Veterans Benefits Services	7,502,000	942,000	n/a	8,444,000
TOTALS	44,796,000	27,344,000	11,805,000	83,945,000

Of the \$45 million identified as specifically benefitting the wounded, about one-third was spent to provide transportation to and from the hospital, lodging for family at the hospital, and care and comfort at the hospital. Another one-third was spent to provide Advocacy and Awareness and Veterans Benefits Services (to assist with VA processes). That leaves one-third spent to provide direct supports (i.e., General Financial Assistance, Building/Adapting Home, etc.) to these families. Based on information from the Defense Manpower Data Center, there were about 6,800 wounded in action per year from January 2006 to December 2007.² If half of those families received equal amounts of General Financial Assistance, Employment Services, TBI Support and Caregiver Training assistance, that would calculate to about \$3,200 per family.

² <http://siadapp.dmdc.osd.mil/personnel/CASUALTY/OIF-Total-by-month.pdf> and <http://siadapp.dmdc.osd.mil/personnel/CASUALTY/oefmonth.pdf>



This chart illustrates the number of organizations providing services in each category and total program expenses for that category that were identified as exclusively wounded warrior support. The categories then are positioned within the Model of Support to indicate where they most likely are obtained by families in need. (Numbers will add to more than 46, as some organizations provide services in more than one category.)

Notice the heavy concentration of resources (i.e., Transportation, Care and Comfort, Temporary Housing, Communication Support, and General Financial Assistance) available at the front end of the Model of Support, primarily during the time the service member is inpatient. Also notice that many supports provided at home, while indirectly benefitting family members, focus on the service member (i.e., Guide Dogs, Veterans Benefits Services, Adaptive Sports, Advocacy and Awareness, and Employment Services). Only four categories extend the direct support to family members: Build or Adapt Homes, General Financial Assistance, Counseling Services, and Scholarships.

Our research indicates two main areas for strengthening non-profit assistance to wounded warrior families. The first is to make it easier for case managers and family members to know which organizations provide what types of assistance to which clientele. The second is to extend the attention and resources expended to care for and encourage wounded warrior families at the hospital to meet the most underserved needs of these families as they prepare to make the transition home and become fully engaged in providing 24/7 care to their veteran. Those needs include:

- Building and adapting homes.
- Respite-care services.
- Community resource coordination.
- Caregiver employment services.
- Family and individual mental-health services.
- Financial management services.
- Long-term assisted-living services that consider age, medical and rehabilitative needs unique to this generation of severely injured.

Again, American Supports You is not an exhaustive list of non-profit organizations that provide assistance to wounded warrior families; however, it does represent a large portion, and the data gleaned from them can help identify areas where more NPO focus may be warranted.

Veterans Service Organizations and Military Associations

It is important to note that veterans service organizations provide countless hours of volunteer time and direct financial-aid programs to a wide population of veterans (wounded and non-wounded). Collectively, they provide a tremendous service to the veteran population through legislative advocacy; helping with VA-claim submission and appeal processes; and providing other direct supports through established charitable foundations within their organizations. While they all serve the wounded and their families in various ways, they generally have a much broader mission – thus, their resources are focused primarily on that broader mission. Even those exclusive to the wounded (i.e., Disabled Vets, Military Order of the Purple Heart, etc.) extend a large amount of their resources toward legislative and

advocacy work for the longer-term benefit of their members. While there are many VSOs, those listed below are some of the best-known:

- AMVETS
- Blinded Veterans Association
- The American Legion
- Disabled American Veterans
- Jewish War Veterans
- Military Order of the Purple Heart
- Paralyzed Veterans of America
- Veterans of Foreign Wars
- Vietnam Veterans of America

Equally important are the many and varied professional military associations that round out the non-profit-sector resources to which many families turn with unmet emergency needs. These organizations vary in size, mission and membership, but all provide various professional, advocacy, outreach and direct support to their membership and the military service they represent. The following names just a few:

- Air Force Association
- Association of the United States Army
- Army Reserve Association
- Marine Corps League
- Military Officers Association of America
- National Guard Association of the US
- National Military Family Association
- Navy League of the United States
- Reserve Officers Association

It would take many more pages to describe each and every support program sponsored by every VSO and MA. However, it is clear that most respond to requests to help wounded warriors and their families. Some have official programs tied to active-duty status (e.g., the VFW Unmet Needs Fund), some sponsor other NPOs (e.g., AUSA Operation Life Transformed Scholarships), and others have developed partnerships with DoD to support the wounded (e.g., the America Legion Heroes to Hometown Program).³

Non-profit organizations, veterans service organizations, and military associations across the country demonstrate that Americans freely and generously give of their leadership and entrepreneurial skills, their time, and their money to show their intense gratitude to, and support of, the U.S. military service members and their families. These organizations, some new, some quite old, have stepped up independently and filled needs as they became aware of them. As we work to increase public awareness of the most urgent and underserved unique support needs of the severely wounded military family, Americans will continue to help non-profits provide the supports these families require so desperately.

³ See Appendix A, page A7 for more details on the Heroes to Hometown Program



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