The Continuum: From Immobility to Mobility to Empowerment

David Holdridge
Vietnam Veterans of America Foundation

Jo Nagels
Vietnam Veterans of America Foundation (VVAF)

Caitlin Wyndham
Vietnam Veterans of America Foundation (VVAF)

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**Center for International Rehabilitation**

Working with the Department of Veterans Affairs Chicago Healthcare System, Northwestern University and the Rehabilitation Institute of Chicago, the Center for International Rehabilitation (CIR) has been designing wheelchairs to fit the specific needs of each disabled individual since 1996. One of their most well-known products is the CIR chair, which is the first chair designed to meet the needs of Afghanistan's harsh environment. The CIR chairs are constructed and distributed in Afghanistan by disabled civilians with parts made under CIR supervision in Pakistan. All of these efforts are a part of the CIR “Wheelchairs for Afghanistan” program.

**The Mobility Project**

The Mobility Project is a non-profit organization that collects and restores used wheelchairs and other medical equipment for persons with disabilities that cannot afford this much-needed equipment. Additionally, in a few of their countries of operation, they have trained disabled civilians to restore wheelchairs and other devices themselves, and they have established the facilities for them to conduct this work. The Mobility Project has made deliveries to Afghanistan and Pakistan, assisting hundreds of landmine victims and other disabled civilians. In addition to delivering the material, their volunteers adjust each mobility device to fit the needs of each particular patient.

Another aspect of the Mobility Project is to enhance further rehabilitation by providing a sports program in the area. The volunteers feel that playing sports is a way to not only rebuild the individual's physical and emotional strength but also to show them exactly how much mobility their new wheelchair brings them. Although this past year's events have halted their project in Afghanistan and Pakistan, they hope to resume operations as soon as possible.

**Conclusion**

There are organizations only a few of the ones making a significant effort to rehabilitate and reintegrate landmine/UXO victims in Afghanistan. By addressing the needs of the entire individual rather than just treating the wound, they are making a huge difference in the lives of people who otherwise would have no chance of surviving in the world. These groups are not only taking steps to rehabilitate the individual but also to rehabilitate the nation by providing job opportunities to enable a desperately struggling country. Although the landmine problem in Afghanistan is one of the most severe and will continue to hinder the country's growth for years to come, these programs provide some much-needed hope for the entire nation.

**References**


**Contact Information**

Susanna Spinkle
Mine Action Information Center
Tel: (540) 568-2810
E-mail: spinkle@jmu.edu

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**Introduction**

For those who are mobility impaired, there is a natural tendency to retreat from the external world and turn inward. Better health for the mobility impaired most often involves a re- engagement with the world around them, transition from the pain to the ordinary by the "rewound-going." Assistive devices combined with a strong will to re-engage are essential that beginning that journey back. They give mobility-impaired persons with disabilities (PWDs) a fighting chance to re-engage.

But is that only the beginning. For successful re-engagement and better health, the mobility impaired must be allowed two other essentials. They must benefit from connection with others who are facing the same challenges. They must also have the right to re-engage in ways that allow their evident value to be put to good use.

As regards connections, there is both power in numbers as PWDs confront societal constraints and comfort as PWDs begin to feel less lonely in their struggle. Herein lies the seeds of movement. Not personal this time, but rather the movement of an idea and a force that can't be denied. And as concerns "good use," embodied here is the notion that men and women need to have a sense of self-worth not only from within but also as reflected by the appreciation of the community for the goods and services PWDs offer.

At the end of the day, rehabilitation and re-engagement is a process. It cannot be addressed successfully by a focus on only one part of that process. Vietnam Veterans of America Foundation (VVAF) activities in Vietnam, supported by the Leaky War Victims Fund of the U.S. Agency for International Development (USAID), subscribe to this philosophy. The mobility impaired need to move, but they need to move in union and then to move toward a productive life. After this, most importantly, they need to move toward creating a national and international movement that has as its heart and soul the belief that all residents of this earth need to live in mutual confidence and respect, not only as an ideal but also because we will perish without such an allegiance to justice.

**From Immobility to Mobility**

The Background in Vietnam

Vietnam, like any country emerging from the effects of war, has many disabled people, both adults and children. Their disabilities can be directly related to the war (e.g., amputation from unexploded ordinance or trauma), or indirectly (e.g., polio as a result of a lack of vaccination programs). Vietnam also seems to have a high proportion of children with cerebral palsy. In Vietnam, there is also the question of diatoms and the effects they may have on children of those who served directly in the military or those simply living in the worst affected areas. In many of these cases, ongoing orthotic care and rehabilitation is needed.

Changes in lifestyles, including an increased use of motor vehicles, tobacco, alcohol and illicit drugs, lead to new health problems and a need for more orthopedic devices. The case load currently seen within the VVAF facilities in Bach Mai and the National Institute for Pediatrics (NIP) indicates a broad range of diseases and impairments that can be related to both the populations of "developing" and "developed" countries. The adult population of patients at Bach Mai suffers from many of the degenerative diseases of aging, e.g., osteoporosis. There is also a large number of people suffering from lifestyle diseases, e.g., stroke and diabetes. Recent newspaper articles indicate the prevalence of diabetes is rising. The pediatric population of patients at NIP indicates a decrease in polio, but an increase in cerebral palsy.

As Vietnam emerges and develops as a country, the population will also change; however, this is likely only to increase the needs for rehabilitation and orthotic/prosthetic devices.

**Inherental Challenge to Treating Immobility in Vietnam**

If you don't have confidence in the diagnosis, you won't have confidence in the prescription. An effective professional seeks to understand the needs, concerns and situation of the physically challenged person. The amateur will sell the product; the professional will suggest solutions to the needs and the problems. It's a totally different approach, the integrity in delivering a skillful service.

Rehabilitation should not be focused
evenly on bracing for selective vocational retraining but should be directed toward enhancing adequate functions in all areas of life. Nor is it limited to restoration after accidental injury, emotional breakdown or acute disease, but it includes developing the capacities of individuals affected by congenital defect, a process that some call habilitation rather than rehabilitation. Capable services also include using appropriate technology to benefit the person. Appropriate technology is a system providing proper fit and alignment based on sound biomechanical principles that suits the needs of the individual but which can be sustained by the country at the most economical and affordable price.

Polypropylene as "Appropriate"

There are some innovative new prostheses for amputees and orthotic devices and technologies being adapted to meet the need for prosthetic care in deprived countries. High-tech devices turn out to be inappropriate in the light of local repair, resistance to harsh circumstances, durability and expense. What is appropriate?

In 1995, the International Society of Prosthetics and Orthotics, with USAID funding, held a conference in Phnom Penh to look closely at the vexing question of appropriate prosthetic technology for the developing world. This discussion had raged for several years, with various agencies adopting wildly differing views on just how we could deal with the huge numbers of limbless people in the world. Although nowadays most care services are committed to rather nicely, locally designed and manufactured modular prosthetic systems and custom orthotic design and fittings, Vietnam still struggles with the acceptance of the use of polypropylene in most of their workshops. The system works well in many countries and is relatively easy to use. It was designed and built by a team of prosthetists and engineers working together. Polypropylene material displays properties that are unique when compared to other materials and has contributed greatly to the quality of our everyday service. Polypropylene, properly applied, will perform functions at a cost that other materials cannot match.

VVF's rehabilitation programs in Vietnam are supported by the Leухy Ваι Victims Fund and implemented in partnership with the rehabilitation departments of two of the leading hospitals in the country under the wings of the Ministry of Health: the NIP and Bach Mai University Hospital, both located in Hanoi. Since 1994, VVF's NIP has produced and distributed more than 6,000 quality thermoplastic braces, helping 4,000 kids to achieve a better, fairer and quality of life. Today, the Institute also provides much-needed medical and rehabilitative services to children suffering from cerebral palsy, clubfoot, and other ailments requiring braces and physical therapy.

**Institution Building**

In both Bach Mai and the NIP, VVF focuses on training existing staff to improve the quality of service at each hospital. A key goal has been to provide educational opportunities for mid-level staff. VVF sponsored several dozen orthotics or prosthetics workshops and enrolled several senior technicians in the International Society of Prosthetics & Orthotics (ISPO)-recognized Vicrot School. At the conclusion of both courses, trained staff will be proficient in the fabrication and correct biomechanical manufacturing of polypropylene orthotic and prosthetic devices. VVF's rehabilitation program at Bach Mai is growing and has been strengthened with the inclusion of four ISPO CAT II recognized graduates from the Vicrot School. To meet the needs of a burgeoning disabled population that cannot make its way to the NIP or Bach Mai, VVF's Mobile Outreach Program has continued to bring basic rehabilitation services directly to the countryside to assist physically challenged children.

Recognizing the critical importance of post-category II training in itself, programs will enhance education and training to promote the institutional will and capacity of the NIP and Bach Mai to achieve excellence in patient care and rehabilitation and extend these services to the selected provinces. This instruction program will not only cover the clinicians but also allied health staff as well. The training will cover all essential technical components as well as provide key documentation of rehabilitation techniques with English skills and "train-the-trainer" program. This aims to ensure the sustainability of training and professional development at the two key hospital workshops and in provincial facilities. When the workshops depart, these local Ministry of Health staff can continue the training effort.

**Stepping Out into the World**

During the past two decades, there has been an increasing recognition that the disabling effects of disease, accidental injury and congenital defect constitute one of the greatest responsibilities not only of medicine but also of society. Rehabilitation workshops should provide the best service possible to anyone requiring a custom brace or prosthesis.

But how should one deal with the loss of self-worth in an individual who has lost not only his earning power but his ability to take care of himself? How can one value the burden of frustration, anxiety, dependency and physical distress that is the daily lot of so many disabled persons? How can one view the effect of the social rejection and job discrimination that are still so prevalent? The fact that many are able to bear these burdens with dignity does not alleviate the problem of disability. That can be done only through an enlightened social policy, which includes not only the ever-expanding rehabilitation program. VVF believes the answer to this lies with the disabled people themselves.

For this reason, VVF believes that after generations of being spoken to, spoken for and spoken about by the able-bodied, people with disabilities can speak for themselves. The technology for empowering groups in any society is a must and is an important tool in ongoing rehabilitation.

**From Mobility to Empowerment**

**User Groups**

In many so-called "developing countries," the transfer of the technology needed to benefit the mobility impaired has preceded the transfer of skills needed to create a context whereby the PWDs can maximize the benefits of assistive devices and whereby the benefits of the technology transfer extend beyond the departure of the expatriate expert.

As described above, the diagnosis, manufacture and application of devices is a highly complex endeavor requiring great coordination among a variety of experts including surgeons, prosthetists, orthotists, and physiotherapists. This combination of expertise is mostly "done" to the patient. The time soon arrives when the PWD makes the long walk back to his/her home and community. In perhaps the majority of cases in the developing world, there is no return visit to those who have helped the person gain mobility. Now they often find themselves in that trough where their accommodation with the new device often produces more discomfort in the immediate than the PWD experienced beforehand. At this juncture, the support and encouragement of the family are critical. Unfortunately, despite an evident love and concern of the family, in most cases they do not know how to help. Nor are they immune to prevailing stereotypes.

Equally important, the "users" of assistive devices can gather with their peers, trade stories and share information about opportunities. At a recent meeting of a new self-help group consisting of patients of Bach Mai University Hospital in Hanoi, a woman was examined by an expatriate clinical supervisor. "When was your prosthesis fitted?" she was asked. "In 1984," replied. Which explained why it was such a bad fit and why she required crutches to walk. When asked "Why have you not returned for a new one?" "Nobody ever told me I could!" This woman had spent several years at home with little
social interaction, simply because getting out of the house was too difficult. She recently thanked VVAF for supporting the establishment of a self-help group as it has made her life worth living again. She says she looks forward to the weekly meetings and has regained some joy in living.

From User Groups to Self-Help Groups
This is the beginning of a potentially wonderful transformation. This is where a group that was begun for rehabilitation and its attendant benefits is now transformed into a group for empowerment. With little facilitation, leaders emerge from within the group. They are authentic because they are also PWDS. They speak from their own experiences. Attendance and participation are encouraged through peer pressure and perceived value, rather than on the basis of obligation to authority. Again, with only modest facilitation from outside, the group naturally evolves from rehabilitation to mutual support to discussions on empowerment and "good use." Talks become increasingly centered on how to use their mobility toward becoming productive and self-sufficient citizens. The group gains access to employment, access to public buildings (schools, hospitals, trains, buses, etc.), access to higher education and then, finally, access to the public policy debate.

At this point, a core of enthusiastic PWDS has moved from rehabilitation to advocacy about "rights," the precursor to the promotion and promulgation of the basic tenets of Vietnamese socialism.

From Self-Help to Empowerment
Parallel to these developments at the community level, there should be a commensurate national and international linking. Support, encouragement and empowerment of PWDS should not be limited to borders. Again, for modest investments, the PWD user/self-help groups should now be linked both physically and electronically with other existing and emerging groups throughout Vietnam.

In the beginning, like most movement, this will indeed be driven by educated PWDS, mostly those from urban areas who have been fortunate enough to benefit from a university education. They are the ones who will take leadership positions with communities and then become part of national coalitions of such emerging leaders nationwide. The low costs and increasing ease of access to electronic communications will keep this "sharing" constant and productive. Best practices and lessons learned can be communicated quickly and effectively across PWD groups throughout the country.

In Vietnam, this has started through the Disability Forum of the Vietnam Union of Friendship Organizations' non-governmental organization (NGO) Resource Centre. Organizations of people with disabilities have made this Forum their own and communicate regularly through the website and an electronic newsletter (see http://forum.uovo.vn/).

Just one step removed, but based on the same principles, both community and national groups can, at low cost, now communicate with their peers all over the world. They can connect, with only small subsidies, to the international PWD movement for support, encouragement and empowerment. The new technologies can do wonders for breaking down the isolation many PWDS feel. Being comfortable with these new technologies also represents part of the skills acquisition process that will heighten employment opportunities in countries such as Vietnam.

As one distinguished PWD said recently, "the day when PWDS can take their rightful place in society and make contribution to society can not arrive until the PWDS themselves are at the heart of the process."

In sum, the sought-after destiny for PWDS is a process. As concerns the mobility impaired, it is a process that begins with the transition from pain to withdrawal to re-engagement, first through the expert help of doctors, orthotists, prosthodontists and physical therapists, and then from the light touch of outside "organization" facilitators, and then finally "of and by" themselves. The lessons learned here are clear. The physical treatments of the mobility impaired cannot be done out of the context of another low-cost process whereby the benefits of mobility are married to reintegration and rights. To provide the wherewithal for mobility without addressing the other needs of the PWD is wasteful.

At the end of the day, the PWD movement is no more or less than a justice issue, justice defined as "right relations." A world where all persons are mutually dependent and respectful. To be part of the PWD movement in Vietnam is to participate in moving the world closer to justice.

"All photos courtesy of VVAF"

Contact Information
Vietnam Veterans of America Foundation 15 Dieu Dung St. Ba Dinh District, Hanoi Vietnam
Tel: 84 4 733 9444 Fax: 84 4 733 9445 E-mail: holdidgo@vtcm.vn Website: http://www.vva.org

Handicap International

Introduction
HI focuses its work on countries with a low level of development and a high degree of conflict with the goal of helping vulnerable people. In Africa, HI contributes to mine clearance, mine risk education, mine data collection, and victims' rights programs. HI carries out such programs in several countries, including Angola, Chad, the Democratic Republic of Congo, Ethiopia, Mozambique and Senegal. Two significant HI programs in Africa are in Sierra Leone and Guinea Bissau.

Victim Assistance in Sierra Leone
The Sierra Leone program is not landmine-specific, but rather helps all people with disabilities, a category that includes landmine victims as well as victims of UXO and improvised explosive devices (IEDs). HI is working with the Ministry of Health in this program that aims to "build a sustainable network of competence and facilities that will enhance the reintegration, general well-being and promotion of the rights of the physically disabled and psychologically suffering population." The program focuses on orthopedic services, psychological support and reintegration (both social and economic) of people with disabilities into society. This initiative, which is funded by One Love Sierra Leone—a British charity formed in 1999 "in response to