

# The Challenge of Prosthetic Services in Developing Countries

Providing landmine victims and other disabled persons with the support and services they need to recover can be a challenging process in developing countries. The author describes that a holistic approach to rehabilitative care is necessary and applies this principle to community-based rehabilitation (CBR).

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## Introduction

It is important for those who develop victim assistance programs in Central America to understand that comprehensive prosthetic and orthotic rehabilitation efforts can be far more significant than simply providing an artificial limb or brace. Furthermore, program developers should be aware of how their own personal values, attitudes and beliefs (regarding people with disabilities and develop-

ing countries) affect important program decisions. Their values and attitudes contribute toward a variety of competing interests among program developers, health professionals and service recipients. These interests influence such choices as where to locate a program, what constitutes appropriate technology and training, and whether or not to rely on local or international staff. These decisions will ultimately affect program relevance, quality and sustainability.

Although there are typically several prosthetic program models, a holistic approach to CBR can be very effective toward addressing larger disability issues regarding social and economic inclusion

for the disabled. Disability advocates, non-governmental organizations (NGOs), funding agents and policy makers should forward a clear vision about the need to support people with disabilities in developing countries as a means of promoting democracy and raising the bar for social justice.

## Disability Stereotypes

Inadequate support for victim assistance in both developed and underdeveloped countries can often be traced to discrimination against the disabled. Throughout history and in most cultures, attitudes toward people with disabilities have been exceedingly negative. The disabled are often viewed as objects of charity or pity; they are seen as sick, dangerous or as a menace to others. They are also sometimes characterized or stereotyped as burdens to the families or the society that will have to care for them. In Central America and the United States, people with disabilities—especially children—are often paraded on stage to raise money for rehabilitation services. While well-intentioned, this kind of activity reinforces innumerable negative stereotypes.

Historically, the disabled have always occupied the bottom rung of the social and economic ladder. Even in developed industrial nations unemployment rates for people with disabilities are more than 10 times that of people without disabilities, even among those having proven capabilities. The human rights of the disabled are routinely ignored, and their social participation is markedly diminished because of societal attitudes. Rehabilitation program developers that are conscious of disability stereotypes and their impact on victims can provide comprehensive quality rehabilitation services

by promoting a positive image of people with disabilities.

## Prosthetic Rehabilitation and Program Models

While enormously challenging because of high cost, specialized training, and questions of appropriate technology and sustainability, the development of CBR victim assistance programs is essential. The lack or frequent failure of CBR programs and the inability to meet the needs of the disabled in developing countries illustrates the difficulty of creating and sustaining rehabilitation projects. Start-up costs in Central America are high. Even the most basic machinery is expensive, costing tens of thousands of dollars. Prosthetic and orthotic materials and components vary enormously in price and availability, but even limbs produced with the most basic components cost hundreds of dollars. Moreover, training and technical expertise can be quite hard to obtain.

In general, prosthetic programs fall within a relatively small range of service models. These can be characterized as: large-scale production programs, recycling programs, transport programs and local community-based programs. Each service model has distinct advantages and disadvantages. Large, externally funded programs emphasize optimum production and skill development for technicians. They tend to measure success as the number of prostheses produced. This model is by far the most expensive and difficult to sustain, particularly without funding from a developed country. Large programs, at least initially, rely on foreign expertise and seem to function in accordance with funding cycles. Typically—particularly when starting out—this type of program can offer a full range of services and can accommodate a large patient base.

Recycling programs or projects that use prosthetic components from northern countries are often started by individuals who are committed to multiple agendas. Recycling can provide much-needed components that projects in developing countries typically cannot afford. They are also appealing because of the concept

of recycling itself. The tremendous waste of medical materials and supplies, particularly in the United States, drives people crazy. What better way to make use of expensive medical materials and equipment than to ship them off to developing countries for good use? However, in the world of prosthetics, this can be hugely problematic. For example, in order to be useful and cost-effective, prosthetics must be disassembled so that their components are still usable. This process must be done by people with at least minimal training, which is very time consuming. The components are seldom interchangeable. Technicians in developing countries may misuse components, thus ensuring poor-quality prostheses. What happens when an individual is given a state-of-the-art, recycled artificial limb (e.g., a high-tech titanium knee joint) and for his/her next prosthesis, he/she only has the option of a much more basic prosthesis with a wooden or plastic knee? Additionally, recycling can create negative image issues for people with disabilities, since the implicit message is that what developed countries throw away is good enough for those in developing countries.

Some programs transport people who have suffered amputations to developed countries for state-of-the-art medical services. In some instances, this can be very helpful. Patients with unusual medical issues requiring specialized surgery may need to travel to a developed country to receive the necessary service. However, careful consideration must be given in identifying individuals for this type of service, particularly with children. Transporting people away from their friends, family and much-needed social support system after suffering the trauma of an amputation can be devastating. In Nicaragua, a young man lost both legs after being trapped in the mudslide caused by Hurricane Mitch. He witnessed his family of 13 disappear underneath a wall of mud as he was running away; his entire family was killed. Soon after this incident, he was whisked off to the United States to receive brand new artificial limbs. Despite the new "state-of-the-art" prostheses, his post-accident mental and emotional trauma was so se-



■ Mario Icaza crafts a new prosthesis.

vere that he could not walk or even leave his house in a wheelchair. Local rehabilitation programs emphasize people learning to help themselves and to solve their own problems. The "Walking Unidos" prosthetic program in Nicaragua employs no foreign staff, is governed by a local board and trains people who have themselves suffered amputations to become skilled technicians. Using International Red Cross components and some recycled ones, purchasing only essential equipment and having a small cost-effective facility are just a few of the reasons why this program can operate for about \$78,000 (U.S.) per year. Yet, the project produces over 100 upper and lower extremity limbs per year, does countless repairs on prostheses and has begun to address some orthotic needs. Local programs do not initially yield the kind of production statistics or patient base comparable to the larger-funded programs. However, if small programs can be sustained over time, future comparisons may be especially interesting.

"Walking Unidos" and similar programs ("Transitions" in Guatemala and "PODES" in El Salvador) have many positive aspects and might be viewed as examples of the best practices. However, this service model has some inherent problems as well. The success of local prosthetic programs requires high-level



■ Dr. Esteban and his clinic staff create a prosthetic cast.





■ In order to be cost-effective, prostheses must be disassembled.

financial and relational commitments from NGOs, and significant expertise in program development. Small prosthetic programs and their NGO partners are constantly spending inordinate amounts of time fundraising and procuring small grants. Sustainability for these grassroots projects also requires high-level local leadership skills and a great degree of trust between partners. Currently, large government programs (such as the U.S. Agency for International Development (USAID)) with extensive reporting and costly oversight requirements make it impractical to administer small grants. The result is a "catch-22" dilemma in which large prosthetic programs cannot be sustained once funding cycles end, and small programs cannot be funded by large organizations in a cost-effective manner.

### Technology

There is much debate over what programs offering prosthetic services are most effective. Professionals can be quite passionate about what technology and machinery is most appropriate and what type of training and credentials are needed to produce and fit quality prosthetic devices. Rehabilitation professionals have a wide range of views about whether or not to use recycled components, what (if any) certification is necessary, and what materials and equipment constitute appropriate technology. These issues can become so contentious and divisive that it can be difficult for people to work toward common goals.

Many problems emerge around the

issues of training and appropriate technology. If two programs in the same region adopt different technologies, patients will generally opt for the more expensive one. This might be perfectly reasonable and raise the standard quality of limbs unless the program offering superior components cannot be sustained. The result may then be that patients having state-of-the-art prostheses have to adapt to lesser-quality ones. Therefore, technology must be viewed not only from the perspective of quality and most recent technical developments, but also from the perspective of sustainability. Another challenge can arise if a program with little external funding produces a perfectly suitable limb at low cost using more basic components, while a program with greater funding using more expensive components produces a superior limb, thus creating unfair competition resulting in the "low-tech" program's failure. Since well-funded prosthetic workshops are usually dependent on grant cycles, they inevitably cease if the grant is not renewed. When this happens, the result is the absence of any programs. One organization used a high-tech CAD/CAM system in Central America. Frequent power shortages, excessive heat, the inability to have parts on hand and lack of access to local repair people to fix the machine all ensured that the project was usually closed. This resulted in poor people with disabilities traveling long distances only to be turned away because of a variety of technical problems.

### Training

There is much debate over what training and certification prosthetists and various level technicians should have. What credentials are needed to ensure that consistent, high-quality prostheses are produced? Some people say none. Because prosthetic programs in Central America have not been sustained, there are many unemployed, experienced technicians throughout the region who had worked for programs that are no longer in operation. There seems to be some significant progress in the area of training, particularly in El Salvador with the advent of the prosthetic/orthotic program

at Don Bosco University. The newer modular program has received high marks from many people in the field.

### Sustainability

The problem of sustainability for prosthetic programs is evident in developing countries all over the world. It is not unusual to see large programs either sitting idle or with minimal staff. Sometimes when external funding ceases, programs are privatized. This generally results in a diminished quality of prostheses and few or no services for the poor. Presently, it may even be unrealistic for prosthetic programs in developing countries to be self-sustaining for any considerable length of time without long-term commitments from outside sources. However, some innovative attempts have been made to sustain programs by using revenues generated from small businesses. This has had some limited success in Vietnam and in Nicaragua where the Ben Linder Internet Café recently generated enough revenue to begin purchasing one limb per month for someone in need. PODES in El Salvador is producing orthotic and prosthetic components that the project is selling to other programs in order to generate revenue for the program. Some programs in Central America have wisely developed several funding streams, lessening the dependency on any one particular source.

### Holistic Approach to Local Rehabilitation Services

The Polus Center for Social & Economic Development, Inc. is an NGO based in Massachusetts that has been supporting people with disabilities since 1979. The organization promotes social and economic development for people with disabilities, utilizing a unique, holistic approach to CBR. Several demonstration projects (including "Walking Unidos") address disability issues ranging from receiving limbs to obtaining employment, and from eradicating physical and social barriers to influencing public policy. The Ben Linder Internet Café employs disabled citizens and uses rev-

enues to pay for limbs produced at the "Walking Unidos" clinic. The access project, "A City for Everyone" uses the principles of "universal design" to reduce physical and social barriers not just for the disabled, but for all citizens within the city of Leon, Nicaragua. The University of Leon, the Polus Center and many local citizens are now in the planning stage for the development of a "Leadership Institute" that will include people with disabilities in its governance and ultimately impact public policy at both the local and national levels.

Rehabilitation practitioners and service recipients clearly understand the need for programs to have a more holistic approach to victim assistance. Over the years, the Polus Center has, with the help of numerous North American volunteers, conducted dozens of interviews with people throughout Central America who have experienced amputations and who are in need of prosthetic services. Specific themes repeatedly emerged from these interviews. It is readily apparent that an artificial leg or arm is much more of a means than an end. Most individuals state that obtaining a prosthetic limb is important, but that having work is equally, if not more important. People want a leg so that they can work, attend school, go to church, take care of their children and do the things they used to prior to the amputation.

### Values and Beliefs Affect Program Models

CBR programs have a unique way of reflecting the values of those individuals or collectives that have created them. Individuals that emphasize the utilitarian importance of providing as many prostheses as possible will support, develop and advocate for large-scale heavily funded programs. Similarly, groups that are motivated by principles such as reducing medical waste or offering advanced medical technologies as important driving principles will create programs

that reflect these beliefs. It is more than likely that these philosophical underpinnings will result in recycling programs or transport programs. Dual agendas such as combining religious conversion with helping people walk will also result in odd configurations of CBR programs. Proselytizing becomes as or more important than victim assistance. Most rehabilitation programs provide something useful and helpful for people with disabilities. However, they generally fall far short of what is necessary to support people with disabilities in comprehensively meaningful and substantial ways.

The development of quality victim assistance programs begins with sound leadership accompanied by a clear program mission. Programs must reflect the values and needs of the disabled, their family members and their closest advocates. Therefore, people with disabilities and their allies must be included in every aspect of program development and operation. Even with a clear mission and principles, program developers must be conscious of implementing certain safeguards to protect against competing program interests. These competing interests such as funding/personnel decisions, competition between NGOs, site location, training, and appropriate technology and components will always influence program models and outcomes. Therefore, the only prudent way to ensure that a program maintains its original integrity, mission and organizational transparency is through public oversight and the full inclusion of people with disabilities.

Successful rehabilitation programs must employ planning methods that give local people the opportunity to provide solutions that are culturally appropriate and relevant to the lives of service recipients. To ensure program relevance, the Polus Center (with the help of volunteers) conducts dozens of team interviews with people who are disabled. Information gathered from interviews is then processed in a group forum, which results in a program blueprint that is carefully

crafted to provide services that are coherent with the wants and needs of people with disabilities. This approach is based on the fundamental premise that the overarching problem for people with disabilities is a societal one. Providing quality mobility devices is only an initial step in helping victims live meaningful and productive lives within their communities. It is essential that rehabilitation programs engage in a more holistic approach to rehabilitation. This entails developing a broader range of initiatives that help eradicate physical and social barriers that limit the economic and social status of the disabled. In this sense, raising awareness about discrimination and the importance of including people with disabilities in all aspects of community life is an essential element of CBR services. ■

*\*All photos courtesy of Peroski Photography.*

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■ A clinic worker meets with a landmine survivor.