

Proposal to Develop Standards for Wheelchair Provision Services:

The International Wheelchair Quality and Standards Organizing Committee:

Whirlwind Wheelchair International, Motivation, Center for International Rehabilitation

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Background

Prior to 1980, wheelchairs for active use in the rugged conditions prevalent in developing countries were virtually non-existent. In 1980, Ralf Hotchkiss of Whirlwind Wheelchair International (Whirlwind) began to design "appropriate wheelchairs"; chairs that could be built in developing countries from locally available parts and materials, and that could be locally repaired or replaced. The chairs were made to withstand rigorous daily use. In 1991, Motivation Charitable Trust (MCT), based in Bristol, England, entered the field of appropriate wheelchair design for developing countries. Motivation worked from the technical base created by Whirlwind and developed program initiatives and training projects in five key areas to address the broad range of needs of wheelchair users. The five key areas include poverty alleviation, rights, capacity development (of organizations and individuals), services and products. The Center for International Rehabilitation (CIR), in Chicago, began its wheelchair efforts in 1998 by developing a regionally based wheelchair distribution and training strategy that couples central fabrication of wheelchair kits with local assembly, distribution and repair by people with disabilities. CIR collaborated with Whirlwind on the design of an adjustable, appropriate wheelchair for this program and the two organizations have been working closely since. Handicap International, based in France and Belgium, and the Vietnam Veterans of America Foundation, based in Washington, DC, have also been involved in the field. In addition many national groups in developing countries have been working towards finding local solutions to the problem of wheelchair provision.

Efforts by all of these organizations resulted in great advances in appropriate wheelchair design, training and distribution for active use in developing countries, but the total number of wheelchairs produced was relatively small, due in large part to the lack of funds available for wheelchair purchases. Generally, people who need wheelchairs are amongst the poorest and must rely on their governments, international development organizations, and charitable organizations to purchase the wheelchairs they need.

During the 1990's, several organizations began to purchase and distribute hospital style wheelchairs around the world for free. Other organizations concentrated on gathering second hand discarded wheelchairs from North America and Europe and shipping them to developing countries. This considerable influx of donated, largely inappropriate wheelchairs in developing countries has precipitated concern amongst the other groups that are also providing wheelchairs in many of these same countries. In general these donated wheelchairs typically don't fit the user properly nor do they function adequately in the environment to which they are exposed. In addition, the distribution of large numbers of donated wheelchairs in the market area of an existing local wheelchair manufacturer can seriously damage their business.

In October of 2004, representatives from Whirlwind, MCT and CIR met in Washington, DC to discuss the potential for creating a consortium that would address the needs of wheelchair users in developing countries. At this meeting the group decided to initially focus on wheelchair provision services, and identified two primary goals. The first is to draft standards for the design, production, distribution and service of wheelchairs for use in developing countries. The second goal is to develop and implement strategies for the larger scale production of appropriate wheelchairs for developing countries. A working group meeting will be organized to include individuals and organizations including partner groups. This working group meeting is tentatively scheduled for mid-2005 in Uganda. Following the meeting in Uganda, the working group will draft standards in three areas of wheelchair provision: products, service and training. The standards document will be presented at a Wheelchair Consensus Conference that WHO and USAID propose to sponsor in early 2006. The conference will provide a forum for other groups to comment, discuss and modify the draft standards developed by this working group.

Defining the Problem

The root of the problem is the disproportionate number of people with disabilities in developing countries. As noted in the June 24, 2003 USAID Annual Program Statement, "conservative estimates put the number of people with disabilities in developing countries at close to half a billion. Of these, an estimated twenty million require wheelchairs to be mobile." Most people in developing countries who need a wheelchair don't have one, and those who do often have chairs donated by international humanitarian aid organizations. Typically, these free wheelchairs are of poor quality and do little to contribute to the socio-economic integration of the wheelchair user.

An inherent problem is that donors operate under a charity model rather than an independent living model. Wheelchair users in developing countries often cannot afford to pay for their own wheelchairs, so government agencies, development organizations, and charitable and religious institutions act as consumers instead. The usual market forces of consumer-based supply and demand are absent: end users are disenfranchised from the design, production and selection processes and become passive recipients of charity rather than empowered consumers. When donors focus their attention on the product instead of the end users, the distribution of wheelchairs takes precedence over the socio-economic integration of people with disabilities into their communities.

Another issue compounding the need for wheelchairs in the developing world is the problem of donor organizations defining disability as solely a matter of impairment and personal mobility to be solved with wheelchairs. Disability, however, is a socio-economic problem as well as a physical one. The issue is not simply that millions of people are physically immobilized, but that this often prevents them from receiving an education, marrying, having families, working to support themselves or their families, or otherwise participating in their communities. Disability is a problem of socio-economic immobility as much as physical immobility.

This perspective is problematic because it views disability and the need for wheelchairs in a paradigm of a humanitarian aid crisis or medical emergency in need of immediate treatment rather than as a normal-albeit occasionally traumatic and frequently inconvenient-part of life in much of the world that requires a sustainable capacity for locally appropriate solutions. Many organizations clearly state their goals in terms of number of wheelchairs to distribute and not in terms of what people will actually accomplish with the chairs. Disability must be seen as an ongoing part of life within local social, cultural, economic, and political contexts-and not as a medical emergency to be solved if we can only charitably give away enough wheelchairs to those in need. The technology is only part of the solution.

The problems associated with the current production and distribution of wheelchairs in developing countries can be identified as follows:

- 1) Donated wheelchairs are usually not appropriate for conditions in developing countries. Most imported wheelchairs are based on American and European designs from the mid-20th century for indoor home and institutional use. These designs were not intended for outdoor use on unpaved terrain. They break easily, but are not easily repaired because spare parts and the equipment necessary to weld alloys are not usually locally available.
- 2) There are no widely accepted appropriate standards to ensure quality. With few exceptions, wheelchairs donated or sold in developing countries do not meet uniform standards. Those that do are based on standards designed for the developed world, which are not stringent enough to adequately test chairs under the more rigorous conditions and use in developing countries.
- 3) There are no prescription or fitting standards. Donated and imported chairs are often "one size fits all" and distributed without cushions or an appropriate seating configuration. A wheelchair that is not properly fit to the user, or comes without a cushion, may increase the risk of secondary conditions such as pressure sores (which are potentially lethal), shoulder injuries, or spinal deformity. In a best-case scenario, inappropriate and ill-fitting chairs do not provide any significant improvement to the users' mobility, independence, or integration into their community.
- 4) There are few training programs that teach the proper prescription, fitting and use of wheelchairs. Wheelchairs that are donated under charitable programs are often delivered without any training on how to properly match the wheelchair user to his wheelchair through assessment, prescription and fitting. Nor is training typically provided to the user to ensure adequate working knowledge of the capabilities and limitations of the chair.

The Solution: Part 1 - International Standards on Wheelchair Provision Services

The broad objectives of the consortium are to address both the quality and quantity of appropriate wheelchairs being disbursed through professional, comprehensive wheelchair provision services in developing countries. It is proposed that these objectives be achieved by developing a series of standards that apply to three key activity areas of wheelchair provision: products, service and training.

1) Products

Generally, products refer to wheeled mobility products (wheelchairs and tricycles), but may also include a host of other products such as cushions and more complex seating, or alternative propulsion mechanisms. The working group will initially focus on adult wheelchairs. Product standards will protect the users, the purchasers and the service providers and will give confidence that basic standards of strength, durability and functionality are being achieved. They will also ensure that the products are regionally appropriate.

Product standards will also include wheelchair testing standards, which are directly related to wheelchair design and production. The Working Group will develop what Whirlwind has named Extended ISO or EISO standards to increase the quality of wheelchairs produced for developing countries. These EISO tests subject the chairs to more appropriate measures of the forces that a wheelchair is likely to be subjected to by an active user in the rougher rural and urban conditions prevalent in the developing world. The ISO standards for strength, safety, and durability of wheelchairs have only existed for "Western" wheelchairs since 1985, although prior to that there were similar ANSI/RESNA standards. Over the last five years, both Whirlwind and Motivation have designed methods that provided local wheelchair manufacturers in developing countries with simple and inexpensive ways to test their own wheelchairs for strength, safety, and durability.

2) Service

Service refers to the process of matching a wheelchair user with an appropriate wheelchair. This includes assessment, prescription, fitting and basic training on the use and maintenance of the wheelchair. Service also refers to the repair and/or refitting of wheelchairs. Applying a standardised approach to the delivery of wheelchairs, in terms of comprehensive assessment, prescription, fitting and basic training for users (i.e. the service), will give greater assurance that the needs of the individual client

are being provided for in an educated and professional manner. Standards applied in such a way will encourage the development of consistent, high quality client oriented services. Similarly, individuals involved in service provision (be they wheelchair users, health care professionals or others) would benefit greatly from the introduction of standards in training. The provision and delivery of wheelchairs is often seen as a simple, non-demanding process. The complexity of user needs, product range and characteristics, and the importance of training and education are often dismissed due to ignorance, and many wheelchairs are distributed using a classic 'charity model' on the assumption that any wheelchair is better than no wheelchair.

3) Training

Training relates to the training provided to those involved in all elements of wheelchair provision be it from a technical perspective (particularly the manufacturing of wheelchairs) or a clinical perspective (i.e. the service). Training standards will be the basis of professionalizing wheelchair provision. The provision of effective, tailored mobility is vital for a wheelchair user. For users to gain maximum advantage and benefit, the process of wheelchair provision should be professionalized through the application of comprehensive, standardised training to ensure those providing the services have a solid foundation of knowledge relating to the needs of different disabilities so that they are able to deliver a comprehensive service. The Working Group would take its lead in this area from Motivation, which established a wheelchair technologists' certificate program at the TATCOT training centre in Tanzania.

The introduction and application of standards for products, services and training will primarily ensure that wheelchair users around the world have the confidence that;

- " their individual needs are being given primary priority,
- " choices are being assessed and made with their involvement,
- " wheelchairs meet basic standards of strength, durability and functionality, and
- " those involved in the process understand the complexity of the issues facing them.

Standards will also provide guidance to those wishing to support wheelchair provision around the world (governments, NGOs and individuals), with assurance that the products and processes they are involved with meet user needs and that money is being spent effectively.

The Solution: Part 2 - Increase the Number of High Quality Appropriate Wheelchairs

There are two basic approaches to increasing the number of high quality appropriate wheelchairs. The first is to support and develop local wheelchair production (local tech) and distribution services. The second is to initiate a more centrally focused production to cover wider geographical areas. Both approaches will result in greater numbers of appropriate chairs and the correct approach for each environment will depend on many issues such as material availability, skills availability, needs of the user groups, and the existence of competent groups to manage production.

When the needs of the end user are considered first, the most appropriate wheelchair (not merely the cheapest) can be provided in conjunction with other targeted assistance, thus enabling the wheelchair rider to go to school, get a job, and participate in community life.

"Local tech" can briefly be defined as utilizing locally available materials (although not necessarily locally manufactured) rather than specific, imported materials; local skilled labor rather than clinicians with Northern biomedical training; and design appropriate to local needs, use, and body culture rather than design imported from a foreign context. By appropriate technology or "local tech," we do not mean wheelchairs that are specifically and only appropriate to users in the Third World, as though this was a homogenous category. We mean appropriate relative to local contexts of manufacture, distribution, and use in order to ensure that wheelchairs are designed and manufactured to best serve the needs of their end users. Bicycle technology is often appropriate for component materials because it is inexpensive and readily available throughout the world.

Although larger scale production is now more feasible with the recent expansion of the global economy, there still is a need for technology and production processes to be designed so that a small wheelchair-building business can be set up with a minimum of tools, equipment, and capital investment, with the entire process accessible so that a wheelchair user can perform all wheelchair construction activities. Coupling "local tech" with the provision of simple jigs and fixtures can be an effective way to increase the number of wheelchairs that can be produced in small shops.

Similarly, a regional distribution strategy that combines central fabrication with local training and delivery could yield desirable results. This strategy would utilize regionally appropriate wheelchair designs and decrease the cost of manufacturing by increasing the number of units produced at a single site, while not sacrificing the benefits of local service provision. Training programs, targeting wheelchair users and other people with disabilities, that focus on the fitting, use and maintenance, and repair of the wheelchair can successfully contribute to social reintegration. Further, localizing the training programs enables them to be offered in the local language and be adapted for cultural sensitivities.

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