

#### THE REPUBLIC OF UGANDA MINISTRY OF HEALTH Disability Prevention and Rehabilitation NATIONAL WHEELCHAIR COMMITTEE

## The Status of the Wheelchair in Uganda

## A Report of

A survey study conducted to determine the demand, availability, quality of production, usage, and affordability of wheelchairs in Uganda.

### Sponsored by

## NAD

The Norwegian Association of the Disabled

By Mary Florence Mukisa

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## Write, therefore, what you have seen, what is now and what will take place later.

**Revelation 1:19** 

#### 'A wheelchair helped me to be known in the village. At one time I did not exist. After I got a wheelchair, I suddenly became known in the village as the wheelchair boy'

**Obbo Stephen** 

(While presenting the importance of a wheelchair to Kireka Focus Group Discussion October 2006)

# UNAPD believes that persons with physical Disability have as much to contribute to National development as anyone else. To do this, PWPDs must be supported by society to develop their potential to levels that will facilitate their own contribution.

(UNAPD Manual for induction of new members 2003)

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This work is dedicated to you, the person crawling in dust, mud and water just to survive, about whom and for whom this undertaking was undertaken.

#### PREFACE

*The status of the wheelchair in Uganda* is a report of a study commissioned by the National Wheelchair Committee to examine the demand, availability and quality of production of wheelchairs in Uganda. The study also looked into the usage and affordability of wheelchairs in the country.

The production of this report will go a long way in addressing the primary hurdle in the provision of quality wheelchairs to those who need them i.e. lack of information on producers and their production capacity in Uganda.

The information generated in this study is going to aid the National wheelchair Committee to enhance its control and supervisory oversight on local wheelchair production as well as on quality control on imported wheelchairs.

The identified challenges and capacity building needs of wheelchair producers will guide the National Wheelchair Committee in developing specific interventions towards improving local production and reducing the dependency on imported wheelchairs.

This report has improved awareness on the enormous need for wheelchairs in the country, the concept of a Quality Wheelchair together with the needs of wheelchair users. This information shall be useful in the formulation of policy, production standards, minimum requirements and may be a law pertaining to wheelchair production, provision and use in the Uganda. The evidence of the enormous need for wheelchairs shall be used to highlight the responsibility of government to address the needs of people needing wheelchairs.

I am grateful that this report has come out at a time when the Ministry of Health is beginning to actively address the issues of wheelchairs and wheelchair use in the country. The recommendations of the report are going to be critically examined with a view to implement them as far as possible to address the needs of Wheelchair users in Uganda.

Dr. Stanley Bubikire Principal Medical Officer Ministry of Health – DPAR

#### FOREWARD

To date, the issues of disability are no longer matters of mere advocacy to ameliorate life of the disabled person; rather disability is now a matter of human rights of profitable citizens unfairly neglected by society and governments, about whom a lot of international charters have been committed.

Uganda is a signatory to all International Human Rights Conventions and by ratifying these conventions; the Government commits itself to ensure that everyone within the country enjoys the human rights covered by these conventions.

The World Programme of Action (WPA) Concerning Disabled Persons (1982) set out to promote effective measures for prevention of disability, rehabilitation of those persons already disabled and the realization of goals for the full participation of persons with disabilities in social life and development. This meant providing opportunities to PWDs, equal to those available to the whole population and ensuring that they too have an equal share in social and economic development justified by their living conditions.

The 22 United Nations Standard Rules on the equalization of opportunities for persons with disabilities which were an outcome of WPA, recognized the necessity of addressing individual needs of PWDs as well as the shortcomings of society. The rules affirm the responsibility of governments to address disability, and emphasize the role of organizations of disabled persons (DPOs) in playing a leading role as partners in the process of developing policies, legislation and programmes for PWDs. Key among the Standard Rules is the right to Support Services, to which a wheel chair is one of the focal items.

Support services imply the supply and development of due services to PWDs, including devices to assist them increase their level of independence in their daily living and to exercise their rights as human entities.

Article 20 of the United Nations Convention on the Rights of Persons with Disabilities which Uganda has already signed, requires State Parties who are signatories to the Convention to take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities by facilitating access by persons with disabilities to quality mobility aids, assistive technologies and forms of live assistance and intermediaries , including making them available at affordable cost.

While the National Wheelchair Committee braces itself to address the enormous problem of improving availability, affordability and quality of wheelchairs, it is worthwhile to note that there is no actual data on producers or their production capacity. It is not even clear whether the beneficiaries are aware of the presence of the wheelchair producers in Uganda and what it entails to get a wheelchair.

Using international estimates it is believed that, Uganda may need up to approximately 1,500,000 wheelchairs for its population with mobility challenges. This need is far from being satisfied. The search for ways and means of making

quality wheelchairs more available, to which this study is a step in the right direction, is a welcome decision.

Just like matters of disability have ceased to be advocacy issues, so have wheelchairs ceased to be a luxury realizable to only a few lucky people. Wheelchairs are part of the right to fair life to those who need them. Crawling is not only inhuman but also restrictive to a person's development. It should be detested and addressed in such a way as to effectively solve the mobility problems of those in need of wheelchairs.

We in UNAPD are looking expectantly to the day when all people who need wheelchairs shall get them as part of observance and respect of their human rights, but not as an expression of pity or benevolent will.

As a wheelchair user myself, I am hopeful that the recommendations of this study will be implemented.

For God and my Country

James E. Mwandha CHAIRMAN UNAPD

Hon. James Mwandha, is chairman of Uganda National Action on Physical Disability (UNAPD), an indigenous advocacy and pressure organization for people with physical disabilities. The Organization strives to ensure that people with physical disabilities enjoy their full rights and access all services available within their environments to enable them live fulfilled lives.

#### ACKNOWLEDGEMENTS

The production of this report, I believe, shall go a long way in addressing key issues in the provision of quality wheelchairs to those who need them. However, the production of this report would not have been complete without the sustained and sustaining effort of several persons and institutions that gave it their unreserved support and backing, to which we in UNAPD are most grateful and indebted.

As an organization of Physically Disabled Persons, we are the first beneficiaries of quality wheelchairs when they come to be. As such we are very appreciative to the Ministry of Health and NAD for providing funding for this study.

In the same vein we are so indebted to the efforts of Dr. Stanley Bubikire, the Principal Medical Officer DPAR and his staff for their tireless efforts in coordinating the process of this survey especially the funding bit of it, which provided the life blood for the study.

We are very grateful to Hon. James E. Mwandha who in his quest for and devotion to find a better life for PWDs in general and PWPDs in particular, has always been there to give guidance and morale to every endeavour that highlights the plight of People with Disabilities, for his acceptance to write a foreword to this report.

We acknowledge the unfailing support from Mr. Okebe Onya, the UNAPD Treasurer, who enthusiastically made sure that every event of the study was systematically and appropriately documented.

We acknowledge Mr. Sempijja Mpiso, from the National Insurance Commission for his technical advice and support in computerising the data collected and facilitating the whole process of training UNAPD staff in computer aided data analysis.

We reverently recognise the contributions of M/s Rose Bongole and Mr. Fred Ssemakula from the Ministry of Health, Disability Prevention and Rehabilitation Section for their invaluable input in data collection.

We similarly express our gratitude to UNAPD staff, Mr. Mpagi Godfrey and M/s Nawabira Mabel who went forth and hither in search of respondents and information during the survey.

I recognise that not every one who helped us conclude this study and to come up with this report can be mentioned here by name. I therefore wish to thank in a special way everyone from whose hands we found help of all manner; information, counsel, direction, advice or physical nourishment and accommodation during this study.

May God find for each of you a sizeable blessing daily hereinafter; in the morning, at the noon time and even when the sun goes down.

#### *Mary F. Mukia* Executive Director UNAPD and Study Team Leader.

#### ACRONYMS, ABBREVIATIONS AND OPERATIONAL DEFINITIONS

ADD	-	Action on Disability and Development
COMBRA	-	Community Based Rehabilitation Alliance
DPAR	-	Disability Prevention and Rehabilitation Section of the MoH.
DPOs	-	Disabled Persons' Organizations
DRO	-	District Rehabilitation Officer
GYDA	-	Gulu Youth Development Association
IWCPU	-	Inspectorate of Wheelchair Production and Use (Proposed)
MADE	-	Mobility Appliances by Disabled Women Entrepreneurs
MoES	-	Ministry of Education and Sports
MoGLSD	-	Ministry of Gender, Labour and Social Development
МоН	-	Ministry of Health
MOTIVAT	ION-	A British NGO with interests in Wheelchairs
NAD	-	Norwegian Association of the Disabled
NBS	-	National Bureau of Standards
NGO	-	Non-Governmental Organization
NUDIPU	-	National Union of Disabled Persons of Uganda
NWC	-	National Wheelchair Committee
PAFOD	-	Pan African Federation of the disabled
PPDPAA	-	Public Procurement and Disposal of Public Assets Act 2003
PS	-	Permanent Secretary
PWDs	-	People with Disabilities
PWPDs	-	People with Physical Disabilities
SCM	-	Supply Chain Management
UNAPD	-	Uganda National Action on Physical Disability
USDC	-	Uganda Society for Disabled Children
WCF	-	Wheelchair Fund
WPA	-	World Programme of Action concerning Disabled Persons

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#### EXECUTIVE SUMMARY

A wheel chair is an assistive device consisting of a sitting facility for one person mounted on wheels to permit a rolling action to be activated and operated, to facilitate the mobility of a person whose lower limbs or muscles supporting locomotion have temporarily or permanently failed to sustain the action of locomotion, either arising from ill health, permanent disability, advanced age or a combination of these factors.

The object of a wheelchair is to permit reliable, easy, decent and relatively independent movement of a person with impaired locomotion ability *in an accessible physical environment*.

There is a wide cross-section of people using wheelchairs which can easily be categorized into three. First among them are the PWDs who have obvious movement challenges. The second category of wheelchair users is the elderly. i.e. Persons above 60years of age. The third category needing wheelchairs are the temporally users, who use them because they require faster movement beyond their normal ability, as a result of injury, surgery or sudden immobilization of some sort.

The *Status of Wheelchairs in Uganda* is a survey study that was conducted to determine the producers of wheelchairs in Uganda, their knowledge of wheelchair production standards and the demand for, availability, usage, and affordability of wheelchairs in Uganda. The information obtained from the study is meant to facilitate the work and operations of the National Wheelchair Committee (NWC) in providing a policy framework to the Government through the Ministry of Health relating to the production, distribution and use of Wheelchairs in the Country.

Reliable data on the number of people in Uganda, who require wheelchairs, is not available. However taking the world estimate of 6% of every population in the developing world, means that Uganda may require as many as 1,500,000 wheelchairs to adequately meet the demand. Of these, a handful is produced in isolated workshops within the country, while another handful comes from donations from abroad.

In the face of lack of a government issued and supervised policy, law or standards in the production of Wheelchairs, it is obvious that wheelchair production in Uganda is assumptive and usually generic but not based on the assed needs of specific users. Imported wheelchairs too lie on the same lane.

In view of all these challenges, the Ministry of Health in partnership with other stakeholders in wheelchair affairs established a National Wheelchair Committee with a mandate to strategically improve availability of quality wheelchairs that are affordable to users.

This sturdy was born out of such fundamental information needs that the National Wheelchair Committee needed to have so as to govern, guard, and give direction to the National wheelchairs' related affairs in Uganda.

Uganda National Action on Physical Disability (UNAPD) was strategically chosen to conduct this study on account of its profound interest in wheelchairs. People with physical disabilities have a stake in and are the principal beneficiaries of this study.

Since the producers are barely known, the National Wheelchair Committee is not certain whether the producers and potential producers of wheelchairs bear any knowledge of production standards and minimum requirements for the production of wheelchairs.

Equally important but not known with certainty is the demand, availability, usage, and affordability of wheelchairs in Uganda. This study was intended to address these issues.

The Overall aim of the study was to analyze local production of wheelchairs, their affordability, availability and usage in Uganda. The study was therefore designed to achieve the following objectives:

- 1. To establish production capacity of wheelchairs in Uganda.
- 2. To analyze the challenges and needs of wheelchair producers and users;
- 3. To analyze the market range of and demand for wheelchairs from workshops that produce them;
- 4. To analyze the community systems available for wheelchair maintenance and repair.
- 5. To analyze the appropriateness of designs in relation to the environment and the basic needs of wheelchair users
- 6. To analyze the consistency between the users' and the producers' concept of a quality wheelchair.

In order to make the information collected to bear a truly national character, the study was conducted in all the four regions of Uganda in the districts Shown in **Appendix 1**.

#### The history

Wheelchair use seems to have started in the current day China because this is where the earliest recorded inscription of a wheelchair was found dating back to the Sixth Century.

The earliest record of the use of a modern wheelchair was in Spain by a 16<sup>th</sup> Century Spanish King, Phillip II, used a movable chair with an armrest and a legrest.

The first mass production of wheelchairs was for injured soldiers during the American civil war. They were mainly meant to provide easy movement to men recovering from frontline injuries. The next mass production of wheelchairs was during the First World War.

In Uganda, wheelchairs were first made in 1967 by Dr. Ronald Huckstep. This was the first fully durable tubular wheelchair built in Third World countries.

#### The principal study questions:

The principal questions that these survey study set out to find answers for were:

- 1. What is a wheelchair to a wheelchair user?
- 2. What kind of wheelchair does a wheelchair user need?
- 3. What is the demand for wheelchairs in Uganda and how much of that demand is met?
- 4. Who produces wheel chairs in Uganda and what is their market coverage?
- 5. What challenges are faced by wheelchair producers in the country and how can such challenges be addressed?
- 6. What designs are appropriate in relation to the environment and the basic needs of wheelchair users
- 7. Apart from those produced within, where else do wheelchairs used in Uganda come from?
- 8. What arrangements are in place for the maintenance of wheelchairs in the country?
- 9. What is the producers' extent of knowledge of the requirements for and the minimum standards of wheelchair production?

The study design chosen for this work was a *survey design*. Using this design, it was assumed that the information needed by the National wheelchair Committee for its work is actually available all over the country and could be collected by conducting surveys at the appropriate locations and among relevant people to answer the principal questions that research set out to find answers for.

A total of 40 districts which represents 50% of the total number of districts in Uganda were selected for this study but the actual number of Districts contacted for the study was 37. This District coverage represented 92.5% of the districts originally targeted.

The principal sources of data for the study were Interviews, Focus Group Discussions, Administration of Questionnaires and Observations. These were the most viable sources of information using this design. The data was analyzed using qualitative methods based on the SPSS soft ware.

The primary challenge to data collection was that of using telephone interviews. Telephone interviews provided limited time for discussion but also robed one of the face to face interactions and examination of the respondents' body language. There may therefore, be information that did not come out clearly as it would have, if there had been on face to face interaction.

From the confessions, discussions and interactions during the study, it was determined that a Wheelchair is;

- A Means of Physical Mobility;
- A source of social independence;
- An aid to a Flexible lifestyle and independent living;
- A Liberator
- A removal of a hideous barrier on the way to personal independence; development, freedom and enjoyment of the full rights by PWPDs;
- A relief from physical pains such as chest pains, joint pains and muscle pains arising from odd modes of movement;
- A means of decent movement;
- Ability to generate income;
- A means of getting involved in Community and political activities;
- A support to education;
- A helper in parenthood;
- A substitution for Lower Limbs and
- An aid to social interaction.

#### The kind of wheelchair that a wheelchair user needs

A wheelchair should bear some attributes that contribute to its definition as an assistive or orthopedic device. i.e. it should be:

- 1. Based on individual assessment to fit user's impairment and needs.
- 2. Strong enough to sustain the user but light enough to facilitate independent manipulation.
- 3. Durable and technically well designed to avoid inflicting secondary disabilities to the user.
- 4. Smart and elegant in its design to give esteem to the user, easy to maintain and or repair.
- 5. Potable in public transport.
- 6. Practical and functional; permitting the individual to be as active as possible, promoting Social independence and adapted to individual's daily living requirements
- 7. Comfortable;

## Measures that should be put in place to ensure good and quality production of Wheelchairs should include:

- 1. Regulatory policies and standards to guide wheelchair makers should be enforced through the National Bureau of Standards (NBS);
- 2. Regulatory mechanism should be instituted to ensure the quality and appropriateness of wheelchairs that are imported, distributed and used in Uganda;
- 3. Assessing all wheelchairs, including the donated ones for suitability by a qualified person, before being handed over to the user;
- 4. Increasing the availability of trained wheelchair technicians to increase the availability of skilled personnel in wheelchair matters;

- 5. Re-equipping and modernize the existing public workshops;
- 6. Increasing trained technicians in Government regional and district workshops to assess, produce and maintain wheelchairs on cost sharing basis. Also aid local artisans *Jua Kali* to acquire skills in basic wheelchair maintenance;
- 7. Establish wheelchair producing orthopedic workshops in district hospitals to ease assessment, production and maintenance;
- 8. Creating an *Inspectorate of Wheelchair Production and Use (IWCPU*) in the Ministry of Health and staff it with qualified personnel
- 9. Enhance the business capacity of existing private wheelchair producing workshops.
- 10. Link the medical and technical professionals on wheelchair; e.g. linking a physiotherapist's assessment to the technician's production to improve functionality.
- 11. Benchmarking the local workshops with other international producers of wheelchairs.
- 12. Sensitizing the public on the value of a wheelchair to a user and the rights of PWDs.
- 13. Encourage the formation of village associations of wheelchair users so as to strengthen their maintenance and sustain their devices.
- 14. Improve the facilitation and use of the office of the District Rehabilitation Officer (DRO)

#### The reasons for low wheelchair production in Uganda

These were determined as:

- 1. Slow growth in the capacity of producers to match the demand,
- 2. Competition from imported chairs,
- 3. The process of getting a wheelchair is long,
- 4. Lack of capital and accessible capital markets in Uganda,
- 5. Lack of materials,
- 6. No marketing is being done for the products,
- 7. Lack of skilled labour,
- 8. High cost of production,
- 9. Limited market; PWDs want chairs but they cannot afford them,

#### Challenges of wheelchair producers in Uganda

These were summarized as follows:

- 1. Lack of quality control guidelines
- 2. Low demand from users

- 3. Wheelchair market is not a fast growing market
- 4. Wheelchair production requires a lot of electricity which is always not available
- 5. Poor equipment base, especially pipe bending machines
- 6. Marketing the products is a problem
- 7. The cost of inputs is high
- 8. Caster wheels are hard to come by
- 9. There is no skills' upgrading centre in Uganda for wheelchair producers. The nearest is in Tanzania
- 10. Capital for investment is limited or lacking
- 11. Records management is a problem too i.e. Book-keeping, Stores records, maintenance records, costing, ordering and production records

#### How the Wheelchair Producers wish to be assisted through the Wheelchair Fund

The workshops wanted help in the following areas:

- 1. Capitalization of their businesses
- 2. Location of quality materials
- 3. Location and acquisition of appropriate equipment
- 4. Establishment of a training facility for wheelchair production
- 5. Skills Development and capacity building in wheelchair production
- 6. Business skills such as marketing, book-keeping, costing, and management
- 7. Construction of workshops

#### Wheelchairs most suited to the Local Environment

According to the respondents in the survey, the wheelchairs most suited to the environment were ranked as follows:

- The tricycle was considered the most suitable.
- The second most suitable wheelchair was the Huckstep (Kampala Wheelchair).
- the 3-wheeler rigid is more appropriate in the rural dwellings
- Meanwhile the 4-wheeler foldable is more suited for the urban setting where there are smoother roads.
- The motorized wheelchair is excellent in comfort and maneuverability but can only work where there is regular supply of electricity.

#### Technology currently used in wheelchair production

All workshops visited by the study team and were in production, currently use simple hand driven pipe bending machines and welding machines as the key machinery in production. The other equipment is only hand tools. There is no automation and electronic testing of production quality. In conclusion, the wheelchair in Uganda has not had a policy, a regulatory framework or any supervision from any quarter, Government or otherwise. Thereby the provision and use of wheelchairs in Uganda has just been random.

There is no reliable data on the exact, or even the approximate number of people in Uganda who need the support of a wheelchair as a mobility device. However close observation and scrutiny of the Disability leaders' comments, clearly points out to the fact that the need for wheelchairs is empirically large and only a small fraction of that need is met.

The provision of wheelchairs in Uganda is currently done as a matter of expression of goodwill but not as part of observance of the Human Rights of the beneficiaries as citizens.

Over 75% of the wheelchairs in use in Uganda are imported. These imported wheelchairs, despite their comfort and beauty, are difficult to maintain and generally lack spare parts.

#### Recommendations

- 1. Wheelchairs should be taken as part of the human rights of the users and a campaign to this effect should be effected at all levels.
- 2. A wheelchair should bear some attributes that contribute to its definition as an assistive or orthopedic device.
- 3. In the short run however, Government and the National Wheelchair Committee should adopt the guidelines provided in *TATCOT Manuals*.
- 4. There is need to strengthen local production and maintenance of wheelchairs including addressing the technological base used by wheelchair makers.
- 5. There is need for the National Bureau of statistics to conduct a detailed survey on mobility assistive devises using discrete instruments of data capture.
- 6. A lot of sensitization work should be done about wheelchairs
- 7. Research should continue on wheelchairs with an objective to make wheelchair use easier, comfortable, safe and more independent.

#### CHAPTER 1

#### 1.0 INTRODUCTION TO THE STUDY

#### 1.1 Introduction

#### 1.1.1 Introduction to wheelchairs

A wheel chair is an assistive device consisting of a sitting facility for one person mounted on wheels to permit a rolling action to be activated and operated to facilitate the mobility of a person whose lower limbs or muscles supporting locomotion have temporarily or permanently failed to sustain the action of locomotion either arising from ill health, permanent disability, advanced age or a combination of these factors.

The term *Wheelchair is* widely used to refer to any facility of the above description and purpose, used by person with locomotion incapacity. It is distinguished from a wheeled stretcher in that it is to be used while the user is seated. The term is therefore loosely used to mean tricycles, hospital sitting wheelers, hand operated wheelers, Four Wheeler Foldables and motorised rolling chairs, but excludes triscooters.

The object of a wheel chair is to permit reliable, easy, decent and relatively independent movement of a person with impaired locomotion ability *in an accessible physical environment*.

#### 1.1.2 Persons who need support of wheelchairs

There is a wide cross-section of people using wheelchairs who can conviniently be categorised into three. First among them are the PWDs who have obvious movement challenges. Some PWDs are solely dependent on wheelchairs for any movement and there are others who require them in combination with other appliances. Some PWDs start using wheelchairs as they acquire secondary disabilities or as they become older. In Uganda, wheelchair users are increasing in numbers because of the increasing Road Traffic Accident (RTA) burden, which is fast becoming one of the top ten causes of morbidity.<sup>1</sup>

The second category of wheelchair users is the elderly. Persons above 60years are estimated at 800,000, and to reach 1,900,000 by 2030.<sup>2</sup> Older persons are prone to accidents and disabling diseases and more likely to use wheelchairs. The increasing life expectancy in Uganda means that we are expecting more people to live up to 60 years and above. Coming along with the increase in the numbers of older persons shall be increases in old age illnesses and the need for more wheelchairs to manage their conditions.

<sup>&</sup>lt;sup>1</sup> Mulago Hospital, Injury Control Centre Surveillance Report. 2000

<sup>&</sup>lt;sup>2</sup> 2002 National Population and Housing Census

The third category needing wheelchairs are the temporally users, who use them because they require faster movement beyond their normal ability, as a result of injury, surgery or sudden immobilisation of some sort.

Hospitals are expected to be equipped with wheelchairs to ensure easy movement of their patients. International operating standards require that public places such as Airports, Hotels, Shopping Arcades, Institutions of Higher Learning, Government Offices, Conference Halls and Stadiums, etc, should be in possession of wheelchairs to cater for easy movement of their clients with mobility impairments or as preparatory precautions in case of accidents.

The *Status of Wheelchairs in Uganda* is a survey study that was conducted to determine the producers of wheelchairs in Uganda, their knowledge of wheelchair production standards and the demand for, availability, usage, and affordability of wheelchairs in Uganda.

The information obtained from the study is meant to facilitate the work and operations of the National Wheelchair Committee (NWC) in providing a policy framework to the Ministry of Health and the Government of Uganda relating to the production, distribution and use of Wheelchairs in the Country.

#### 1.1.3 The National Wheelchair Committee (NWC)

The Wheelchair Committee is a coalition body which was established in March 2004 as a recommendation of the Regional Wheelchair Conference. The conference was held in the same month in Kampala to analyse the basic issues on wheelchair production. The conference was attended by Uganda, Kenya, Tanzania, and Zambia. Norway and Britain were represented by NAD and Motivation International respectively.

The purpose of the committee is to address issues of quality assurance and access to wheelchairs by persons with disabilities. The NWC comprises of relevant stakeholders in wheelchair affairs. These stakeholders currently include:

- DPOs i.e. NUDIPU and UNAPD;
- NGOs with a bias to disability i.e. ADD, COMBRA, USDC;
- Relevant Government Ministries i.e. MoGLSD, MoES and MOH;
- Wheelchair producers which include at the moment MADE and Mulago Orthopaedic workshop;
- Parliamentary Representative, Hon. James Mwandha.

The activities of this committee to date have included:

- Establishment of the secretariat at the Ministry of Health.
- Developing standards on quality and designs of appropriate wheelchairs to fit the specific needs of wheelchair users.
- Field testing of the Whirlwind wheelchairs from Norway, which, if found suitable for use in the environment, would be promoted for use.

- Carry out a wheelchair cost analysis research
- Research on production and usage of wheelchairs
- Training of relevant professionals in wheelchair related affairs
- Identification and support of local wheelchair producers, and
- To establish a wheelchair fund.

It was agreed that the work of the NWC should for the time being be hosted by the Ministry of Health, Disability Prevention and Rehabilitation Section (DPAR). A secretariat was established at the Ministry of Health with a co-ordinator to co-ordinate activities. It was further agreed that the Principal Medical Officer in charge of DPAR shall automatically be the Head of the Committee. It is hoped that the work of the NWC will eventually be recognised, taken over and owned by the Government of Uganda through the Ministry of Health. NAD is currently providing donor support to the Committee.

#### 1.1.4 The wheelchair fund (WCF)

A functional Wheelchair Fund, as aforementioned, is one of the expected outputs of the NWC. The aim of the wheelchair Fund is to ensure that everyone who requires a wheelchair in Uganda has access to an appropriate wheelchair as a matter of right, regardless of whether they can afford it or not.

The concept of the WCF is to develop a common basket (fund) from which wheelchair producers and users can draw funds for better production and easier purchase of the wheelchairs. The NWC has a duty to develop a clear process and balanced system for the WCF. The committee has to fundraise locally and abroad to fill and sustain the basket, to create awareness on issues pertaining to the wheelchair fund and to ensure equity in its usage and control.

How to build this wheelchair fund is still a debate. A number of ideas have been and are still being fronted especially on the issue of its sustainability.

For such a noble programme to be established and sustained, it was deemed important to make a ground survey on the status quo on wheelchairs in the Country.

#### **1.2** Background to the study

A cross-section of different categories of physical disabilities including persons with spinal injury, cerebral palsy, polio survivors, those disabled though accidents, physiological diseases, the aged and sick depend on wheel chairs for mobility, activities of daily living, economic sustainability, livelihood and development.

An estimated 100-130 million people with disability worldwide need wheelchairs, though less than one percent own or have access to one. It is believed by some international organisations that in developing countries the number could be as high as 6% of the population.

The number of people with disability especially in the developing world is likely underestimated, due to the difficulty in accounting for these somewhat 'forgotten' citizens who spend their lives in back yards.<sup>3</sup> There is therefore a great need for production and usage of wheel chairs to liberate people with disabilities from the backyards of literally everything; family life, economic opportunities, development endeavours, social interaction and even social esteem.

Reliable data on the number of people in Uganda, who require wheelchairs, is not available. Taking the world estimate of 6%, means that Uganda may require as many as 1,500,000 wheelchairs to adequately meet the demand. Of these, a handful is produced in isolated workshops within the country, while another handful comes from donations from abroad.

The lack of adequate local production of wheelchairs has been a longstanding problem, raising dependency on used, reconditioned and donated wheelchairs that are many a time unsuitable in the local terrain and worse still are difficult to maintain and or repair.

In the face of lack of a government issued and supervised policy, law or standards in the production of Wheelchairs, it is obvious that wheelchair production in Uganda is assumptive and usually generic but not based on the assed needs of specific users. Even imported wheelchairs too lie on the same lane.

An overview of the orthopaedic workshops indicates that there are a few Government and Private Workshops that produce and repair wheelchairs. Production, however, is at such low levels that some are just unknown.

In view of all these challenges, the Ministry of Health in partnership with other stakeholders in wheelchair affairs established the National Wheelchair Committee with a mandate to strategically improve availability of quality wheelchairs that are affordable to users.

As the National Wheelchair Committee (NWC) strives to address the issues of quality wheelchairs, there was a realization that there was no data on who produces wheelchairs in Uganda and how much knowledge they posses on the concept of a *Quality Wheelchair*.

A Quality Wheelchair from the point of view of the NWC is one that is:

- Suited to the user's size when seated i.e. It is not too narrow or too wide for the user;
- Made or supplied after an assessment of the user's level of impairment and adapted to the user's needs and impairment;
- Which the user can alight on and off without encumbrance;
- Strong enough to sustain the weight of the user;
- Light enough for the user to easily and independently manipulate;
- Has a good and easy to use breaking system;

<sup>&</sup>lt;sup>3</sup> Wheelchair Fund Concept paper Min. of Health Disability Section, 2004

- Durable;
- Strong enough to be used in the local terrain;
- Technically well designed such as not to inflict secondary disabilities to the user; or worsen the existing disability;
- Easy to maintain and or repair;
- Which does not occupy more space than is necessary;
- Which is smooth, smart and elegant such as to give a degree of esteem to the user;
- Can easily be transported along with the user in case of long distance travel especially by public means.

NWC therefore needed to precisely know who produces and who can maintain wheelchairs in Uganda, where those producers are located, what geographical area their supply covers and what their production capacity is visa viz their assumed geographical coverage.

It was also necessary for the NWC to bear knowledge on the operational, marketing and may be even the technological challenges faced by the wheelchair producers. In addition the NWC also needed to acclimatize itself with the appropriateness of the wheelchair designs in relation to the environment where they intended to be used and the basic needs of wheelchair users.

This sturdy was born out of such fundamental information needs that the National Wheelchair Committee needed to have so as to govern, guard, and give direction to the National wheelchairs' related affairs in Uganda.

Uganda National Action on Physical Disability (UNAPD) was strategically chosen to conduct this study on account of its profound interest in wheelchairs. The people with physical disabilities have a stake in and are going to be the principal beneficiaries of this study.

As an organization of people with physical Disabilities, with membership in 26 Districts, UNAPD had a comparative logistical and knowledge advantage to undertake the study. In addition, UNAPD has had the experience of procuring and distributing wheelchairs for the welfare of its members.

#### 1.3 Statement of problem

Uganda needs approximately an average of 4,464 wheelchairs per district in all the 80 Districts. It is estimated by district authorities that there are 500 wheelchairs on average in use in each district, which in the opinion of the NWC is a fairly exaggerated and an unlikely situation. Even if this were true, Uganda still remains with a big challenge of covering a deficit of over 3,964 wheelchairs per District.

This abnormally large disparity between the need and availability of wheelchairs makes wheelchairs appear a great luxury to those who need them, yet they ought not to be such.

It is common place to find hearted celebrations and a concordance of speeches whenever a district receives as much as only 10 wheelchairs donated from abroad,

(which they may never be able to maintain anyway). This confirms that a wheelchair is indeed a luxury to many disabled Africans and Ugandans in particular. For Uganda as a country to address this situation meaningfully, there is need to strengthen local production of wheelchairs.

While the national steering committee braces itself to address the enormous problem of improving the availability and affordability of quality wheelchairs, there is no actual data on available producers, their production capacity, locality, and geographical areas served. It is not even clear whether the beneficiaries are aware of the presence of the wheelchair producers and the minimum costs required to acquire one.

Since the producers are barely known, the National Wheelchair Committee is not certain whether the producers and potential producers of wheelchairs bear any knowledge of production standards and minimum requirements for the production of wheelchairs.

Equally important bur not known with certainty is the demand, availability, usage, and affordability of wheelchairs in Uganda. This study was intended to address these issues.

#### 1.4 Overall aim of the study

The aim of the survey was to analyse local production of wheelchairs, their affordability, availability and usage in Uganda.

#### 1.5 Objectives of the study

In order to attain the overall aim of this study and for the NWC to clearly be able to take a leading role in governing, guarding and promoting the concept of a quality wheelchair and bridging the information gap on wheelchairs in the country, this survey study was designed to achieve the following objectives:

- 1. To establish production capacity of wheelchairs in Uganda.
- 2. To analyse the challenges and needs of wheelchair producers and users;
- 3. To analyse the market range of and demand for wheelchairs from workshops that produce them;
- 4. To analyse the community systems available for wheelchair maintenance and repair.
- 5. To analyse the appropriateness of designs in relation to the environment and the basic needs of wheelchair users
- 6. To examine the consistency between the users' and the producers' concept of a quality wheelchair.

#### 1.6 Expected outputs of the survey

This survey was anticipated to bring forth:

- 1. Data on workshops that engage in production and maintenance of wheelchairs
- 2. To list sources of wheel chairs other those produced locally in Uganda
- 3. A list other sources for repair and maintenance of wheelchairs other than workshops
- 4. A description of the community system currently available for wheelchair maintenance and repair
- 5. Catalogues of challenges of wheelchair users and producers.
- 6. A comparative analysis of the users and producers' concept of a quality wheelchair.

#### 1.7 Justification

The National Wheelchair Committee is mandated to govern, guard and guide, National wheelchair related affairs in Uganda. One of the activities of the National wheelchair Committee is the operationalisation of the Wheelchair Fund intended to promote the availability of Quality Wheelchairs to those in need. Yet there is no adequate information to facilitate this endeavour and mandate.

In the same vein, a large need for wheelchairs lies unsatisfied. There is, however, barely any knowledge among those who need wheelchairs of who produces them and similarly the producers have no contact with their potential market which is in those who need their products. This is an unsatisfactory scenario in the wheelchair supply chain which has to be addressed.

This study therefore helps in the following areas:

- The study has increased awareness on the enormous need for wheelchairs in the country, the concept of a Quality Wheelchair and the pronounced needs of wheelchair users. This information shall be useful in the formulation of policy, production standards, minimum requirements and may be a law pertaining to wheelchair production, provision and use.
- The information generated in this study is going to aid the National wheelchair Committee to enhance its control and supervisory oversight on local wheelchair production as well as quality control of wheelchair importation.
- Who is who in wheelchair production and repair in the country is now known, this knowledge is going to facilitate the campaign for increased availability of quality but affordable wheelchairs. It will also be used to strengthen the linkage between production centres, the buyers and the beneficiaries.

- The identified challenges and capacity building needs of wheelchair producers will guide the National Wheelchair Committee in developing specific interventions towards improving local production and reducing the dependency on imported wheelchairs that have often times proved difficult to maintain.
- The Direct networking and linkage of the workshops to the Wheelchair Fund shall improve mobilisation of the artisans for capacity building, improvement of their market coverage, and production quality control.
- The findings provide data that can be used for fundraising, advocacy and lobbying on various aspects relating to wheelchair production, distribution and usage.
- The glaring evidence of the enormous need for wheelchairs should be used to highlight the responsibility of government to respect and address the human rights of people needing wheelchairs.

#### 1.8 The scope of study

#### 1.8.1 Geographical Scope of the Study

In order to make the information collected to bear a truly national character, the study was conducted in all the four regions of Uganda in the districts Shown in **Appendix 1**.

#### 1.8.2 Content Scope of the study

The primary objective of this study was to establish:

- a) Data on workshops that engage in production and maintenance of wheelchairs.
- b) The other sources of wheelchairs for users in Uganda
- c) Sources for repair and maintenance of wheelchairs other than workshops
- d) The challenges and needs of wheelchair producers;
- e) The market range of and demand for wheelchairs from workshops that produce them;
- f) The appropriateness of designs in relation to the basic needs of wheelchair users and the environment.
- g) The technical knowledge of local wheelchair producers and maintainers from the perspective of a wheelchair as an orthopaedic appliance.

#### CHAPTER 2

#### 2.0 THE WHEELCHAIR (LITERATURE REVIEW)

A wheel chair as already sited above is an assistive device consisting of a sitting facility for one person mounted on wheels to permit a rolling action to be activated and operated to facilitate the mobility of a person whose lower limbs or muscles supporting locomotion have temporarily or permanently failed to sustain the action of locomotion.

Wheelchairs are often the only source of mobility for someone with mobility challenges. But, like many other orthopaedic appliances, wheelchairs should be tailor made to fit the individual user and therefore should not be fully subjected to mass and generic production. Besides making wheelchairs suit the person in terms of size, they should also be made to suit the disability. A person with spinal injury for instance, needs a wheelchair adapted to protecting the person against pressure sores, incontinence and loss of sensitivity.

There are wheelchairs that can propel themselves. There are those especially for the sick, where one must depend on others for any movement. In Uganda, and especially among polio survivors, tricycles are more popular because additional functions can be attached to improve their functionality. It can for instance be adapted to assist in income generating activities.

#### 2.1 The History of a wheelchair

#### 2.1.1 The early wheelchairs

The use of wheelchairs is fairly an old matter. Wheelchair use seems to have started in the current day China because this is where the earliest recorded inscription of a wheelchair was found dating back to the Sixth Century. An image of a wheelchair was found inscribed on stone in a Chinese Sarcophagus. This suggests that the sarcophagus may have been that of a wheelchair user and the inscription was meant to be a reminder of that fact.

The earliest record of the use of a modern wheelchair was in Spain. The 16<sup>th</sup> Century Spanish King, Phillip II, used a movable chair with an armrest and a legrest. It is recorded that this was an elaborate chair and was then referred to as an *Invalid's Chair*. From the name of the chair, it is clear that King Phillip II used this devise because of a disability. The Chair was then made elaborate to suit Phillip's royal status.

In 1700, King Louis XIV of France used a wheelchair called *Roulette* for moving about while recovering from an operation. This is the first recorded incidence of a sick person using a wheelchair. It seems that this laid the foundation for use of wheelchairs in medical facilities.

In the 18<sup>th</sup> Century in the United States of America, a Wheelchair was found well built but its maker to date remains unknown. It had two large wooden front wheels and one caster rear wheel. Although it was an isolated case, this was quite a modern hand driven wheelchair. In 1869, the first fully modelled wheelchair was built. It was designed for pushing. This was followed closely in 1870, when the first tricycle was build to improve the independence of the wheelchair users by providing a riding gear attached to the front wheel.

The first mass production of wheelchairs was for injured soldiers during the American civil war. They were mainly meant to provide easy movement to men recovering from frontline injuries. The Wheelchairs were either used in isolation or in combination with crutches. These wheelchairs were fashioned after the 18<sup>th</sup> Century wheelchair.

In 1894 the first official patent was given in the United States of America to build wheelchairs. This was the first government registered and controlled production of Wheelchairs. The conditions of the registration patent were that; the producers of the wheelchairs were to make the chairs with fixed frames, adjustable surfaces, firm wicker seats and larger rear wheels for easier self propulsion.

The next mass production of wheelchairs was during the First World War. The Wheelchairs produced during the World War I were with wooden frames, wicker seats, adjustable armrests and foot-rests, large spoked font wheels and one rear caster wheel. The spoked wheels were meant to reduce the weight of the chair to the rider and increase grip compared to the wooden wheels.

#### 2.1.2 Other important dates relating to wheelchairs

Other important dates relating to wheelchairs are:

- 1924, the first electric scooter was made;
- 1932, Herbert Everest built the first folding wheelchair, for his paraplegic friend Harold Jennings;
- 1937, Herbert Everest and Harold Jennings formed the first company, Everest and Jennings Ltd (E&J), to devote all its work on building Wheelchairs.
- 1950, Everest and Jennings Ltd made the first motorised wheelchair. This wheelchair was later remodelled to include transistor control which could easily be adapted to the needs of the user;
- 1952, the first sports wheelchairs were used at Mandeville Rehabilitation Centre in England;
- 1964, the first Para-Olympic Games were played using wheelchairs in Tokyo, Japan;

• 1980, Everest and Jennings Ltd made the Micro-Compressor controlled and powered wheelchair which is more adaptable and noiseless. (Vide Appendix 3)

In all these changes in the development of the wheelchair, four key issues stand out concerning the wheelchair:

- First the chair has been, all along, adapted to the user;
- Secondly, the chair has been made to make user physically comfortable;
- In the third place, the chair has been, in addition to assisting the user in movement, been made to be attractive to the eye and to comfort the self-worth of the user;
- Finally the production of wheelchairs has over history, fallen under some regulatory institution to ensure that the producers conform to some minimum production standards in order to deliver the dream i.e. *The quality Wheelchair*.

#### 2.2 The History of wheelchairs in Uganda

**Marc Krizack<sup>4</sup>** (2006) Wheelchair History Made in Uganda (The Second of an Occasional Series on Wheelchair History) wrote that:

Around 1967, while in Uganda, Dr. Ronald Huckstep designed a wheelchair made from old chair frames and bicycle parts. This was the first fully durable, tubular wheelchair built in 3rd world countries. The cost of the materials varied between \$50 and \$100. By 1975, more than one thousand had been produced. In 1975, Huckstep published a manual on "Simple Wheelchairs and other Vehicles" in which he discussed his work in Uganda.

Huckstep recognized that imported wheelchairs were usually too expensive, broke down easily, and were difficult to repair because of a lack of spare parts. He decided to make his initial prototypes out of old broken metal frame chairs. These were repaired by welding, and a supporting frame was added for the wheels. This was necessary because the wheels he used were bicycle wheels which needed to be supported on both sides of the hub. Canvas seats and backs were made out of old canvas mail bags. Caster wheels, or as he called them, "bogie" wheels, were taken off old hospital carts. Wooden chock blocks were used for brakes. More sophisticated versions of this chair were developed from this initial prototype.

<sup>&</sup>lt;sup>4</sup> Wheelchair History Made in Uganda by Marc Krizack <u>krizack@sfsu.edu</u>

#### 2.2.1 Huckstep's Design Considerations

Huckstep knew that a good wheelchair in Uganda, or anywhere in the developing world for that matter, needed to be cheap. In fact, for Huckstep, cost seems to have been the overriding design criteria. That meant that a wheelchair needed to be made from locally available materials and strong enough to stand up under tough conditions, including mud, dust, water, and rough roads. But he also knew that its design needed to be simple enough to be manufactured locally with semi-skilled labour.

Huckstep also grappled with the various compromises that have to be made when designing a wheelchair; that is to be independently operated rather than pushed. On the one hand, a chair needed to be low enough to the ground so that the user could climb in and out of it fairly easily, yet high enough to clear potholes and small drains. The narrowest possible chair is desirable so the rider can go down small paths and through the common narrow doorways in houses, yet in order to use available bicycle wheels, the frame had to be wider than a standard wheelchair to accommodate the outer axle supports. It was Huckstep's opinion that this was an acceptable trade-off because the cost of the wheelchair would be much higher if bicycle wheels could not be used. Because of this design decision, the Huckstep is essentially an outdoor wheelchair.

Today, most third world wheelchairs are built using large wheels mounted on a hub which spins on a fixed axle and needs to be supported only on the inside. This may be a function of wheelchair riders making their own decisions regarding the features they want in a wheelchair. Or it may be that a hub that can be made from locally available materials has been around since about 1982.

#### 2.2.2 Rigid or foldable?

Huckstep also confronted the issue of foldability. In general, non-foldable wheelchairs, known as "rigid" wheelchairs, are less expensive to produce and tend to be stronger. The latter fact is especially true when compared to standard hospital-style wheelchairs. However, a foldable wheelchair is much easier to transport on buses. In this instance, Huckstep came down on the side of a non-foldable wheelchair. He reasoned that since Uganda had few private cars, the opportunities for folding a chair for transport were few. He also argued that most taxis and buses had roof racks, so a non-folding chair could easily be carried on the roof.

Hotchkiss, who generally designs wheelchairs that fold, noted that "*a bus driver will usually charge double or triple to load a person's non-folding wheelchair on top of the bus.*" He says that the Huckstep chair is not allowed on many forms of inter-city transportation.

#### 2.2.3 Advantages of Huckstep design

Despite advances in wheelchair design, the Huckstep continues to offer a number of advantages. The relatively long wheel base allows it to descend most curbs and to climb small curbs. The three-wheel design, with the two large wheels in the front and the third bogie (caster) wheel trailing in the back center, maintains good traction over rough but relatively level ground. This design keeps both of the large wheels on the ground at all times. A single trailing wheel not only becomes obstructed less, but can also be tilted out of a pothole. It also acts as a prop to prevent the wheelchair tilting backwards when going uphill.

The Huckstep also continues to cost less than folding wheelchairs in part because it is easier to fabricate. Many of these savings also translate into lower start-up costs for a small wheelchair building business. The use of old chairs as the main frame has the advantage that the basic chair is available without having to build jigs or purchase a tubing bender. The use of off-the-shelf bicycle wheels means there is no need to make a hub or spoke the large wheels, as with the Hotchkiss Whirlwind. The Huckstep's plywood seat and back require no sewing of material. "In general," noted Hotchkiss, "less training of production workers is required with the Huckstep than with a chair like the Whirlwind." Hotchkiss estimates that when produced in quantity, the Huckstep might be 20% cheaper than the Whirlwind.

#### 2.2.4 Disadvantages

Most of the Huckstep's main disadvantages seem to stem from the large wheels being located in the front. They can make it difficult for people with significant disabilities to transfer in and out of the wheelchair. They make it impossible to pull up close to a table or a work bench. Front wheel drive tends to slip going uphill over sandy soil, and it can be more difficult for a person to push himself /herself than if the wheels were located in the rear.

The Huckstep has two other problematic features. The fixed footrests cannot be raised over obstacles, limiting its use for taller people and making it more difficult for a person assisting the wheelchair rider. The hard plywood is very conducive to pressure sores for people with spinal cord injuries, although less of a problem for those people with sensation in their legs and buttocks. Hotchkiss noted that in Uganda there is no procedure for prescribing wheelchairs, so if a spinal cord injured person is given a Huckstep, that's the chair they're stuck with.

Dr. Huckstep has not been unaware of this problem. When a Huckstep wheelchair is to be given to a paraplegic, Dr. Huckstep would require that the seat and back be padded with foam or some other suitable padding covered by waterproof material to hold it in place. However, many spinal cord injured persons in Uganda receive the Huckstep without padding. The chair is currently built in the rehabilitation wing of a government hospital.

#### 2.2.5 Revolutionary for its time

Although there have been many advances in low-cost, appropriate technology wheelchair design since the mid-1960's, the Huckstep was truly revolutionary for its time. It was the first reliable mode of independent mobility for many disabled Ugandans. By allowing disability activists to get out into society it may well have been the most significant factor in propelling the Ugandan disability rights movement to the position it enjoys today at the forefront of the disability rights movement in Africa.

#### 2.3 The concepts of a wheelchair and wheelchair production

**Ministry of Health - Disability Section**, *Wheelchair Fund Concept paper*, (2004) noted that "A cross-section of different categories of physical disabilities including persons with spinal injury, cerebral palsy, polio survivors, those disabled though accidents, physiological diseases, the aged and sick depend on wheel chairs for mobility, and activities of daily living ...."

This statement implies that a wheelchair is not just an item that is being asked for, as a matter of fashion and verbosity of disability needs, rather it is a device needed to transform life and livelihoods of many people who otherwise would remain ghastly crawling about and appear jadedly burdensome.

According to **Khalifan-Khalifan (PAFOD**) - *Disability Knowledge and Research* (*Spring 2004*) "Wheelchairs liberate people with disabilities who need them. Without them (wheelchairs), many people with disabilities end up prisoners in their own homes. A wheelchair enables participation in family and community activities, and promotes one from economic empowerment to advocacy for human rights....."

Khalifan here views a wheelchair as a liberator and liberation to a person in need of one. Without a wheelchair, many persons with disabilities are condemned to home imprisonment, never going out, ever being dependent and always suffering the indecency and humiliation of having to crawl. If a wheelchair is introduced to such a person, Khalifan believes it is a kind of loosening from a prison and an enlargement of one's scope and sphere of life which is an invaluable transformation.

On the need for production and usage of wheel chairs, *the Wheelchair foundation Newsletter*, (2003) Commented that "An estimated 100-130 million people with disability worldwide need wheelchairs, though less than one percent own or have access to one. It is believed by some international organisations that in developing countries the number could be as high as 6% of the population. The number of people with disability is likely underestimated, due to the difficulty in accounting for *'forgotten'* citizens who spend their lives in back yards"

If this assertion by the News letter is something to go by, in Uganda, about 1,500,000 wheelchairs are needed and if only 1% is available then on average the Country has only a limping 250,000 wheelchairs leaving a gap of 1,475,000 wanted but unsupplied. The need for and the current production and usage of wheelchairs is dreadfully unbalanced and more must be done alleviate the imbalance.

In his figurative comments **Heini Saraste**: "What a wonderful life" Disabled Peoples' International –Finland, Piekasamaki, Finland RT-Print -Oy, (2001) Page 89: said:

"A wheelchair is a luxury to many disabled Africans. Many disabled people in developing countries have to crawl around or they have to go on all fours".

Going on *Fours* was Heini Sarste's figurative expression of the "Wonderful" life of crawling that the disabled African goes through in his own country. Wonderful indeed because the site of a living human being, who could lead a better life if provided with an assistive devise, going on four, leaves one wondering about the extent of hardship this person reality goes through. Such life and hardship can be greatly liberated and transformed by acquisition of a Wheelchair.

In UNAPD, the Mission is "To ensure that UNAPD becomes a leading action oriented organization of People with Physical Disabilities dedicated to the removal of barriers in society that prevent them (People with Physical Disabilities) from enjoying full rights" **UNAPD Five Year Strategic Plan 2003-2008**, **Page 9**.

One of the rights of a person is exercising his or her full human potential in social and economic endeavour to satisfy his or her human needs. Nonetheless, this can only be achieved if one is mobile. The absence of mobility can be such a hideous barrier to the enjoyment of the full rights of a person with a disability that it impedes all social, economic and development activities to which a wheel chair can be such a relief. Supplying a wheelchair to a person who needs one is removing a barrier on his or her way to personal independence, development and freedom.

It can therefore empirically be concluded that, wheelchairs should be taken as part of respect and fulfillment of the human rights of persons in need of them. They are great liberation to many who would otherwise be in prison in their own homes and above all, wheelchairs should be seen as removal of big barriers and benevolent transformation to the lives of the users in their personal development. As such, adequate quality wheelchairs should be produced and made easily available to those in need. This is the concept of *a wheelchair and wheelchair production*.

#### 2.4 The Quality of a Wheelchair

Concerning the concepts of a quality wheelchair, **Otto Bock**, one of the Leading personalities in wheelchair production in the United States of America, made several statements.

**Otto Bock** wrote: "Mobility has many facets and means something different for everyone: Physical mobility, social independence, a flexible lifestyle. This also applies to persons who are dependent on a wheelchair or other mobility aids. They are entitled to expect mobility aids that are practical and functional, but also in harmony with their personal lifestyle. On vacation or for everyday use - our power wheelchairs and power add-on drives are reliable companions under all circumstances and allow you to master every challenge.

With its manoeuvrability and different versions, our active wheelchairs are simply fun. Combined with their modern design, they correspond to your desire for activity and individuality. Active and lightweight wheelchairs, power wheelchairs and power add-on Drives. Otto Bock provides high-quality products to improve your quality of life. Our wheelchairs ensure optimal fittings, especially in geriatrics and in case of rheumatic complaints or neurological deficits. They can be adapted to your individual requirements.

Your mobility and independence are our top priority. That's why we offer you a great number of special controls tailored to your individual need. Our special seats combine great sitting comfort with an appealing design. And it is a matter of course that they can be optimally adjusted to your personal requirements"<sup>5</sup>.

These statements can be interpreted to imply that an assistive devise like a wheel chair should clearly and definitely fit into the lifestyle of an individual and should not significantly inhibit that individual leading a chosen lifestyle; rather it should be functional enough to be in harmony with the individual's lifestyle.

The key attributes that Otto Bock believes should be in a wheel chair are:

- Practical and functional, permitting the individual to be as active as he/she chooses
- Harmony with the users lifestyle
- Permitting Social independence
- Allowing the user to be a master in every challenge
- Manoeuvrability
- Lightweight
- Adapted to individual requirements
- Comfort
- Appealing in its design

#### 2.5 The wheelchair chain of supply

According to the **Supply-Chain Council (2007)** *Definitions,-* "a Supply Chain is the process that begins with acquiring resources that go towards meeting customer demand for your product or service and ends with getting products to customers and receiving payments for the products or services supplied."<sup>6</sup>

**Imants BVBA** summed up the issues of the supply chain with these words:

"In today's rapidly changing business environment, ever greater demands are being placed on business:

• To provide products and services quicker

<sup>&</sup>lt;sup>5</sup> (Unpublished Papers January 2007. (<u>www.ottobockwheelchairs.org</u>)

<sup>6</sup> Supply-Chain Council Definitions (2007) (http://www.supply-chain.org.)

- With greater added value
- To the correct location with
- No relevant inventory position.

Customers want more quality, design, innovation, choice, convenience and service, and they want to spend less money, effort, time and risk". The supply chain of a company should involve different departments, ranging from procurement of materials to customer service.<sup>7</sup>

The Supply Chain Council recognizes the Supply Chain Management (SCM) as the combination of the art and science that goes into improving the way your company finds the raw components it needs to make a product or service and deliver it to customers. The following are five basic components of SCM:

**Plan** – *This is the strategic portion of SCM*. You need a strategy for managing all the resources that go toward meeting customer demand for your product or service. A big piece of planning is developing a set of metrics to monitor the supply chain so that it is efficient, costs less and delivers high quality and value to customers.

**Source** – *Choose the suppliers that will deliver the goods and services you need to create your product.* Develop a set of pricing, delivery and payment processes with suppliers and create metrics for monitoring and improving the relationships. And put together processes for managing the inventory of goods and services you receive from suppliers, including receiving shipments, verifying them, transferring them to your manufacturing facilities and authorizing supplier payments.

**Make** – *This is the manufacturing step.* Schedule the activities necessary for production, testing, packaging and preparation for delivery. As the most metric-intensive portion of the supply chain, measure quality levels, production output and worker productivity.

**Deliver** – *This is the part that many insiders refer to as logistics.* Co-ordinate the receipt of orders from customers, develop a network of warehouses, pick carriers to get products to customers and set up an invoicing system to receive payments.

**Return** – *The problem part of the supply chain*. Create a network for receiving defective and excess products back from customers and supporting customers who have problems with delivered products.

**The Wheelchair foundation Newsletter, (2003),** noted that: - "An estimated 100-130 million people with disability worldwide need wheelchairs, though less than one percent own or have access to one. It is believed by some international organizations that in developing countries the number could be as high as 6% of the population......."<sup>8</sup>

<sup>&</sup>lt;sup>7</sup> Imants BVBA, Management Presentations Inc. (*December 2006*) Supply Chain Management Guide (*http://www.mananagementpresentations.com/ibi.htm*)

<sup>&</sup>lt;sup>8</sup> Wheelchair foundation Newsletter, (2003),
From the foregoing discourse, it is apparent that the disparity in wheelchairs reaching those who need them in Uganda and even in other parts of the world may not only be a matter of poverty and inability to afford wheelchairs per say, it might significantly also be a matter of poor or incomplete Chain of Supply. This is most exemplified in Uganda where information on who produces wheelchairs has been hard to come by, yet hundreds of thousands of people with physical Disabilities lie in need of wheelchairs but without information on how and where to get them from including those who could afford or whom someone could buy a wheelchair for.

Conversely, wheelchair users, like an other consumers in our country, want out of the wheelchair they buy; more quality, design, innovation, choice, convenience and service, and they want to spend less money, effort, time and risk to acquire one.

In Uganda where attention to disability issues is just still upcoming, and where records and information are hard to come by, it is still difficult to specify with accuracy everybody who produces wheelchairs in the country and who pays for the aspects in the supply chain for wheelchairs. It is the onus of the National Wheelchair Committee, its partners and wheelchair stakeholders to sort this out and get the deficiency fixed.

# 2.6 What priority is given to wheelchair production?

**Marc Krizack** quoted Hotchkiss a wheelchair maker in relation to the disadvantages of the Huckstep Wheelchairs as saying: "In Uganda there is no procedure for prescribing wheelchairs, so if a spinal cord injured person is given a Huckstep, that's the chair they're stuck with"<sup>9</sup>.

In Uganda as already stated above, attention to disability issues is still a new dimension. However attention is now increasingly being paid to disability because of the growing pressure from the disability movement and international policies. The Disability Act also provides for unhindered mobility for People with Physical Disabilities. The Ministry of Health has established a section in its Headquarters wholly devoted to disability headed by a principal Medical Officer. This Section is now housing the National Wheelchair Committee, whose prime objective is addressing, guarding, governing, guiding and mainstreaming National wheelchairs' related affairs in the Country.

Nevertheless, the challenge of having wheelchair issues documented to permit discrete control and more extensive quality production to meet demand is still a daunting task in the face of resource and information constraints. However effort is steadily being mounted and progress is being registered step by step.

<sup>&</sup>lt;sup>9</sup> Marc Krizack (<u>krizack@sfsu.edu</u>) op cit

# 2.7 Principal Survey Questions.

The principal questions that these survey study set out to find answers for were:

- What is a wheelchair to a wheelchair user?
- What kind of wheelchair does a wheelchair user need?
- What is the demand for wheelchairs in Uganda and how much of that demand is met?
- Who produces, and who can produce wheel chairs in Uganda and what is their market?
- What challenges are faced by wheelchair producers in the country and how can such challenges be addressed?
- What designs are appropriate in relation to the environment and the basic needs of wheelchair users
- Apart from those produced within, where else do wheelchairs used in Uganda come from?
- What arrangements are in place for the maintenance of wheelchairs in the country?
- What is their extent of knowledge of the requirements for and the minimum standards of wheelchair production?

### 3.0 METHODOLOGY

# 3.1 The study design

As earlier aforementioned, Uganda remains with a big challenge of covering a deficit of approximately 3,964 wheelchairs per District that are needed but are not available. In view of this, the Ministry of Health in partnership with other stakeholders established the National Wheelchair Committee in order to strategically improve the availability of affordable quality wheelchairs.

While the National Wheelchair Committee positions itself to address the enormous problem of improving the availability of the much needed affordable quality wheelchairs, there is no data on the available and potential producers, their capacity, location, and geographical areas served.

This sturdy was born out of the need bridge the information gap so that the National Wheelchair Committee can effectively govern, guard, guide, and give direction to the National wheelchair related affairs in Uganda.

In that regard, the study design chosen for this work was a *survey design*. Using this design, it was assumed that the information needed by the National wheelchair Committee for its work is actually available all over the country and could be collected by conducting surveys at the appropriate locations and among relevant people to answer the principal questions that research set out to find answers for.

# 3.2 Selection of study Respondents

# 3.2.1 Selection of Districts for the study

In Selecting the Districts for the study the country was divided into four regions, Central, Western, Eastern and Northern. Thereafter, 10 districts were to be selected at random from each region. This was to make a total of 40 districts which represents 50% of the total number of districts in Uganda.

However as the study progressed, it became apparent that some Districts chosen did not have more value addition to the study in terms of more information than what had already been collected. It was therefore deemed unnecessary to visit them. Therefore the actual number of Districts visited for the study was 37. This District coverage represented 92.5% of the districts originally targeted which was fairly representative. **(Vide Appendix 1)** 

# 3.2.2 Selection of Respondents in the Districts

It was planned that three respondents would be selected for Telephone interview in each of the selected Districts. These three were purposively selected based on their proximity to disability issues. Two respondents were to be leaders in the disability movement, i.e. a District Councillor representing PWDs and the chairperson of the District Union. The third respondent was a Relevant Health Personnel from a District Hospital or the nearest major hospital. The term "*Relevant Health Personnel*" as used here refers to technical persons in District or Regional Hospitals such as an Orthopaedic Technicians, a Physiotherapists, Occupational Therapists or Wheelchair Technologists who could obviously be in possession of knowledge on all or part of the principal study questions. The total number of intended respondents for the telephone interviews was 120.

The rationale for the interviews was that; District Disability leaders in conjunction with the Relevant Health Personnel are more likely to get in touch with wheelchair users as well as producers. They most likely also have general knowledge of the wheelchairs that get into the district.

The interview was intended to analyse disability district leaders' knowledge of local wheelchair production and the extent of the use of those workshops. These interviews were also aimed at obtaining information on affordability and wheelchair design preference and finding out whether People with disabilities and their leaders know who and where they (Producers) are located. This information is crucial for the initial access to wheelchairs by persons who need them and their eventual maintenance and repair.

# 3.2.3 Selection of respondents for Focussed Group Discussions

Three wheelchair user Focus Group Discussions were to be organised in three randomly sampled districts in each region. But the three sampled districts were to be part of the 10 districts originally selected for the study in each region. For respondents to be considered to take part in the Focused Group Discussion, they had to be wheelchair users and aged 18 years and above

The Respondents who participated in the focused group Discussions are shown in **Appendix 2**.

# 3.2.4 Selection of the workshops to be visited

From the information provided by the Focused Group Discussions, workshops producing wheelchairs were listed and the biggest three in region where selected for physical visitation, assessment and face to face interview with the study team. The term *big workshop* from the point of the study team was determined by the apparent quantity of wheelchairs produced by the workshop according to the respondents in The Focus Group Discussions in each region. The total number of workshops anticipated to be visited where 12, but the actual number of Workshops visited was 14 as follows:

- Central Region 4 Workshops
- Northern Region 2 Workshops
- Eastern Region 3 Workshops
- Western Region 5 Workshops

# The List of Workshops visited are shown in Appendix 4

### 3.3 Data collection

The principal sources of data for this study were through Interviews, Focused Group Discussions, Administration of Questionnaires and Observations. These were the most viable sources of information using a survey design. (Vide Appendix 5, 6 and 7)

### 3.4 Data analysis

Data collected in most surveys including this one is qualitative. The data was therefore analysed using qualitative methods based on the SPSS soft ware.

# 3.5 Procedure

# 3.5.1 The Birth and growth of the idea

When the national wheelchair committee was established in 2004 to manage wheelchair related affairs in the country, it became glaringly clear that any interventions into the national wheelchair affairs would not be possible without first establishing the status quo of wheelchair production, usage, challenges and opportunities in Uganda. Such knowledge was recognised as essential for designing and instituting an interventional strategy i.e. the Wheelchair Fund, which includes stepping up quality production, increasing availability and access to quality wheelchairs across the country.

UNAPD as one of the key stakeholders in wheelchairs, with the same need for information, presented the idea of conducting a study to determine the wheelchair status in the country to the National Wheelchair Committee. The idea was accepted and included in the committee workplan. UNAPD also presented to the committee its willingness to curry out the survey.

# 3.5.2 The rationale of choosing UNAPD for the study

The search for information on the status of wheelchairs in Uganda has been a nagging problem in the disability movement and in UNAPD in particular. In the effort to respond to members' demands for wheelchairs, UNAPD needed to understand the level of need for wheelchairs in the country but lacked the means. UNAPD as an organization for physically disabled people had several advantages for carrying out the survey

Primarily, UNAPD as a membership organisation with 26 district member associations of persons with physical disabilities, including wheelchair users, has a fair grip of the conditions of wheelchair users, and the key people who would have appropriate knowledge of the information needed. Further more, the Secretariat in UNAPD had adequate knowledge, the capacity and commitment to carry out the survey with minimum resources.

### 3.5.3 The development of the proposal

The Executive Director UNAPD developed the research proposal based on the expectations of the National Wheelchair Committee. The proposal, including the research instruments, were submitted, discussed with, and were approved by the DPAR Secretariat. An agreement between UNAPD and DPAR was signed and resources transferred to UNAPD to facilitate the study process.

### 3.5.4 Instruments used for data collection,

There were basically three instruments used to collect data; i.e.

- 1. A general questionnaire for leaders in the disability movement and key contact health workers in districts. This was designed to capture information on the general sources of wheelchairs in the districts, and the leaders' knowledge of the extent of need for wheelchairs, how most of their members acquire them and the general challenges members face in acquiring and using the wheelchairs they have.
- 2. The second questionnaire addressed managers of the workshops that produce wheelchairs. Three questionnaires were to be administered per region but priority was given to Kampala to interview more than one workshop. Since the questionnaire was to be conducted on site, direct observation was also to be done by the person interviewing, to assess the capacity of the workshop in producing the wheelchairs.
- 3. The third instrument was an Interview Guide for Focus Group Discussions with wheelchair users. Discussions were held in Kabale, Arua, Gulu, Soroti, and Kireka in Wakiso District.

### 3.5.5 The process of study

The research was implemented in phases:

### Phase 1: Pre-testing:

The Pre-test was conducted by three members of UNAPD staff, headed by the Executive Director. Two meetings were held to discuss and internalise the research objectives, instruments, and process by all the participants. Pre-testing was done by conducting telephone interviews in Mubende and Jinja Districts. The Team met again to discuss the findings of the pre-testing and a few adjustments were made on the research instruments

# Phase 2: Telephone Interviews:

The participating districts were selected by a random sample with each district having an equal chance of being selected. The sampling was done by recording all districts, region by region on small peaces of papers and randomly selecting 10 districts from each region.

Telephone contacts of all District councillors for disability, District Union Chairpersons or their deputies were generated, using a standard contact guide for councillors and district union leaders obtained from the research section of the Parliament of Uganda.

Using these contact telephone numbers, the team was able to identify district medical contacts most appropriate to the district disability movement. The study team placed reliance on the Councillors and Disability Union Leaders because most orthopaedic appliances will not be distributed in a district without the attention of the District Union or the District Councillors for disability who for now provide leadership to persons with disabilities in Districts.

Using the leaders' questionnaires, telephone interviews were conducted with 2-3 leaders per district.

### Phase 3: Visiting Workshops producing wheelchairs

Through telephone interviews in phase II, the working team generated a list of workshops that the interviewees claimed are producing wheelchairs for them. Once again, the workshops listed were segregated by region and 3 workshops were randomly selected from each Region for visitation. Thereafter the team visited the selected workshops to have face to face interviews with management and carry out general assessment.

### 3.5.6 The research Team

The Research team consisted of three key staff of UNAPD and One Board Member. A statistician was later co-opted to help in data analysis. The List of members in the Study team is shown in **Appendix 9**.

### 3.6 Limitations in data collection.

The primary challenge to data collection was that of using telephone interviews. Telephone interviews provide limited time for discussion but also rob one of the face to face interactions and examination of the respondents' body language. There may therefore, be information that did not come out clearly as it would have, if there had been on face to face interaction.

Mobile telephones and their numbers are also not permanent. Some contacts were unsuccessful or simply not available. In a few of the cases like in Kalangala, the team could only get one person to interview by telephone.

Substantial effort to get information from the health personnel failed. There seemed to be a big gap between the disability leaders/ and the health service providers. It was therefore not possible to get all the telephone contacts of the

relevant health providers from the district disability leaders. This proved a poor linkage between the people's leaders and the relevant health providers.

# 3.7 Other Limitations

The study team went to the field with an assumption that the District medical services include wheelchair matters. As the study progressed, it proved that wheelchairs are considered only at national level. The district health services do not seem to have anything to do with wheelchair provision despite their being key orthopaedic appliances. Therefore some of the medical personnel were fairly ignorant of wheelchair issues and this limited data capture.

This was reflected in finding several Regional Orthopaedic Workshops (attached to Regional Referral Hospitals) not having equipment for producing wheelchairs, let alone actual production. Yet many Disability leaders assumed that all Regional Orthopaedic Workshops produce Wheelchairs.

Out of the respondents reached, 6 respondents seemed to know nothing regarding wheelchairs. This represented a complete questionnaire failure.

The cost of activities proved far higher than had been anticipated. This limited the questionnaire coverage, telephone interviews and the number of Focus Group Discussions held.

Lastly there has hardly been any survey in districts as to who needs a wheelchair. Most of the data provided in this survey, in many a case therefore, were mere estimates and assumptions depending on the demand placed on the District Union Chairpersons and Councillors to provide wheelchairs. Only two districts - Mubende and Wakiso provided data attributed to a survey. However the figures they presented were so high and quite unbelievable. The figures explicitly needed a corroborative analysis to confirm their validity.

# 3.8 Data compilation and analysis

After the field activities, data collected was organised and fed into an SPSS programme and analysed using qualitative and descriptive methods. In total 48 questionnaires, 50 telephone interviews and responses from 5 Focus Group Discussions were analysed to come up with this report.

# 4.0 FINDINGS AND ANALYSES

### 4.1 What a wheelchair is to a wheelchair user

According to Otto Bock; a wheelchair manufacturer, a wheelchair bears three properties to its user. It is:

- A Means of Physical Mobility
- A source of social independence
- An aid to a Flexible lifestyle.

In this regard Otto Bock stated that "Mobility has many facets and means something different for everyone; physical mobility, social independence and a flexible lifestyle. This also applies to persons who are dependent on a wheelchair or other mobility aids."

On the other hand, Khalifan, Chairman of PAFOD views a wheelchair as *a Liberator*. Without a wheelchair, a person in need of one is simply condemned to home imprisonment, never going out, ever being dependent and always suffering the indecency and humiliation of having to crawl. If a wheelchair is introduced to such a person, Khalifan believes it is a kind of loosening from a prison and an enlargement of one's scope and sphere of life, which is an invaluable transformation.

To UNAPD, provision of wheelchair is removing a hideous barrier on the way to personal independence, development, freedom and enjoyment of the full rights of a person with a disability.

The Focus Group Discussions around the country were quite telling about what a wheelchair means to the user and what difficulties its absence can wreak. The sombre stories were chilling testimonies of what doing without a wheelchair had been to the lives of those who have been lucky to acquire one. Yet while their testimony spoke for those who attended the Focus Group Discussions. One must bear in mind the many within the vicinity who could not attend such meetings because they lacked the means (the wheelchair) to move from their seclusion. It is also a vivid description of the gruesome experiences and plight of those disabled persons who need but cannot access a wheelchair. The participants in the Focus Group Discussions described the meaning of a wheelchair to PWDs' lives from different angles. Respondents' responses to the Question 2 of the Focus Group Discussion Guide which was seeking to find how the wheelchair has made a difference in their lives yielded these statements:<sup>10</sup>

- I no longer feel chest pains, joint pains and muscle pains and my knees no longer swell
- I no longer crawl on mud, dust and water

<sup>&</sup>lt;sup>10</sup> Responses to Question 2 of the Focus Group Discussion Guide "*How has the wheelchairs improved your life?*" Vide appendix 7.

- I can now sell my mandazi (Doughnuts); it has helped me in my Business.
- It helped me become a Councillor
- I was able to get a wife
- I am able to go for prayers
- It helps me to fend for my self for example fetching water. Before I got a wheelchair I could crawl ands fetch little water at a time
- It helps me travel to school on a daily basis
- I can now carry my baby and move about, even go to the market
- The wheelchair is my legs it helps me to do work and get a living. I carry things; it gives me exercise and helps me avoid dirt.
- The wheelchair saved me from isolation, without a wheelchair I could compare my self with a dead person
- A wheelchair helped me to be known in the village. At one time I did not exist. After I got a wheelchair, I suddenly became known in the village as the wheelchair boy
- It made me friends
- I was able to go to Japan for sports

From the confessions, discussions and interactions foregoing, it can be determined that a Wheelchair is real transformation to the life of a person who needs and acquires one. Judging from the various emotional descriptions and implications that a wheelchair bears to the lives of disabled people, this assistive devise genuinely removes disastrous barriers from the way of disabled persons in diverse dimensions summed here as follows:

A wheelchair is:-

- A Means of Physical Mobility
- A source of social independence
- An aid to a Flexible lifestyle and independent living.
- A Liberator
- A removal of a hideous barrier on the way to personal independence, development, freedom and enjoyment of the full rights
- A relief from physical pains such as chest pains, joint pains and muscle pains arising from odd modes of movement
- A means of decent movement and presentation.
- Ability to generate income.
- A means of getting involved in Community activities.
- A support to education
- A helper in parenthood.
- A substitution for Lower Limbs
- An aid to social interaction

Despite the fact that a wheelchair is so invaluable to wheelchair users as an item that defines their humanity and makes them known persons, this device is at the

moment in Uganda provided as a matter of favour by charitable organizations, faith based institutions or politicians canvassing for votes, principally as a demonstration of goodwill but not as part of observance of the human rights of PWDs, who are a section of the community and are as human as any one else with a right to decent living, physical mobility, social independence and a chosen lifestyle.

### 4.2 What kind of wheelchair does a wheelchair user need?

A wheelchair should bear some attributes that contribute to its definition as an assistive or orthopaedic device. It is such attributes that a user is looking out for in a wheelchair. It is also the same attributes that determine the concept of a quality chair and the users' satisfaction or dissatisfaction with the chair.

### 4.2.1 Satisfaction with Locally made wheelchairs

Question 3 of the questionnaire administered to the District Disability Leaders sought to determine the level of satisfaction that the current wheelchair users have with the locally produced wheelchairs. The question also wanted to find out the reasons for such satisfaction if any.

An analysis of the respondents responses were as in the tables below.

# Table 1: Showing the analysis of reasons for satisfaction with locally produced wheelchairs

No	Reason for satisfaction with Locally	No of	Percentage of
	Produced wheelchairs	Respondents	Respondents
		Accepting reason	Accepting
		for satisfaction	reason
1	Strong and suitable to the local terrain	22	46
2	Spare parts are available	13	27
3	They have carriers for luggage	2	4
4	Designed according to the users specific	8	16
	needs		
5	Models made can climb hills	3	7
	Total	48	100

### 4.2.2 Dissatisfaction with Locally made wheelchairs

Table 2: Showing the analysis of reasons for dissatisfaction with locally produced wheelchairs

No	Reason for dissatisfaction with Locally Produced wheelchairs	No of Respondents Accepting reason for satisfaction	Percentage of Respondents Accepting reason
1	Cannot easily be transported	31	62
2	Too heavy to be managed independently	5	11
3	Hand Pedals are too high(tricycle)	6	15
4	Not comfortable	3	6
5	Not beautiful	1	2
6	Not well balanced	2	4
	Total	48	100

# 4.2.3 Reasons for putting up with Locally Produced wheelchairs despite their disadvantages

Table 3: Showing the analysis of reasons why users put up with locally produced chairs despite their disadvantages

No	Reasons for putting up with Locally Produced wheelchairs despite their disadvantages	No of Respondents Accepting reason for satisfaction	Percentage of Respondents Accepting reason
1	Have no other experience	11	23
2	Have no better choices	35	73
3	Easily available	2	4
	Total	48	100

### 4.2.4 Reasons for the preference for imported wheelchairs

Table 4:	Showing t	the	analysis	of	reasons	for	users'	preference	for	imported
	wheelchair	rs								

No	Reason for preference for imported wheelchairs	No of Respondents giving reason for Preference	Percentage of Respondents in preference
1	Can easily be transported	30	60
3	Light enough to be managed	5	11
	independently		
5	They are comfortable	10	23
6	They are beautiful	1	2
7	They are well balanced	2	4
	Total	48	100

#### 4.2.5 Disadvantages of imported wheelchairs

Table 5: Showing the analysis of reasons for dissatisfaction with imported	
wheelchairs	

No	Reason for dissatisfaction with imported wheelchairs	No of Respondents giving reasons for dissatisfaction	Percentage of Respondents not satisfied
1	Unsuitable to the local terrain	22	46
2	Spare parts are not easily available	13	27
3	They have no carriers for luggage	2	4
4	Designed for specific needs of users in Europe	8	16
5	Models made cannot climb hills	3	7
	Total	48	100

This analysis of wheelchair aspects confirms the realization that a wheelchair should bear some attributes that contribute to its definition as an assistive or orthopaedic device if it is to create quality, support and satisfaction to the user.

Regarding attributes that a wheelchair should bear so as to suit the user, Hon. Kobusingye a female District Councillor in Kabale District Council representing PWDs, who is also a wheelchair user, reiterated that; "*a quality Wheelchair is one which is in harmony with the user's lifestyle*"<sup>11</sup>. The implication of this statement is that a wheelchair should be made to suit and genuinely assist the user constructively by facilitating the user to live a chosen lifestyle without limiting any dimension of that lifestyle.

<sup>&</sup>lt;sup>11</sup> Hon. Kobusingye's presentation to Kabale Focus Group Discussion with the study team. (Oct 2006)

From the point of view of the NWC, a quality wheelchair is one that has the following attributes:

- a) Suited to the user's size when seated i.e. It is not too narrow or too wide for the user
- b) Made or supplied after an assessment of the user's level of impairment and adapted to the user's needs and impairment
- c) Which the user can climb on and off without encumbrance
- d) Strong enough to sustain the weight of the user
- e) Light enough for the user to easily and independently manipulate
- f) Has a good and easy to use breaking system
- g) Durable
- h) Strong enough to be used in the local terrain
- i) Technically well designed such as not to inflict secondary disabilities to the user or worsen the existing disability.
- j) Easy to maintain and or repair
- k) Which does not occupy more space than is necessary
- 1) Which is smooth, smart and elegant such as to give a degree of esteem to the user
- m) Can easily be transported along with the user in case of long distance travel especially by public means
- n) Whose production has gone through a clear and supervised manufacturing process just like is usually done with other life support devises.

According to Otto Bock, a wheelchair manufacturer, a good Wheelchair is one that: <sup>12</sup>

- a) Allows the user to master most challenges as they come
- b) Practical and functional, permitting the individual to be as active as possible
- c) Permitting Social independence and adapted to individual's daily living requirements
- d) Strong enough to sustain the weight of the user
- e) Easily manoeuvrable and light enough for the user to independently manipulate
- f) Comfortable;
- g) Elegantly appealing in its design;

In the perception of a wheelchair user, all the attributes that contribute to and define a wheelchair as an assistive or orthopaedic device, are necessary if it is to create support and satisfaction.

<sup>&</sup>lt;sup>12</sup> Unpublished Papers January 2007. (<u>www.ottobockwheelchairs.org</u>)

# 4.3 What is the demand for wheelchairs in Uganda and how much of that demand is met?

There is no reliable data on the exact, or even the approximate number of people in Uganda who need the support of a wheelchair as a mobility device. This is mainly for the following reasons:

- 1. The National Bureau of Statistics when capturing data on disability during surveys and censuses, only captures disability data in general or in broad categorisations such as Physical Disability, Blindness and Deafness without any pointer to assistive devises. This tendency is a product of ignorance of disability issues and lack of resources for a more detailed disability survey.
- 2. The people in dire need of wheelchairs, in most cases missed out on education and are ignorant of the presence of such assistive devises. If they know at all about wheelchairs, they just do not know how to access them. They live in the backyards of families, are unknown beyond the immediate neighbourhood and above all they are voiceless.
- 3. Some families view a person with a disability needing the support of a wheelchair as burdensome, parasitic and an invalid with no economic contribution to make. Finding and maintaining a wheelchair for such an invalid is thereby considered as committing much needed resources on an unproductive use at high opportunity cost. Thus if a wheelchair has to be found, it has to be a donation.
- 4. There has never been a through study dedicated to find, expose and document those in need of mobility support mainly because of resource constraints both in Government and among wheelchair stakeholders.
- 5. There is no legal consequence or sanction for ignoring the human rights of disabled persons at the moment. If any sanction or sanctions exist at all, they are very lenient. Such important human rights like the right to mobility, decent living and a chosen lifestyle including providing education to a person needing the support of a wheelchair can be ignored with no hick of consequence.

In the absence of reliable data on the exact number of people in Uganda, who require a wheelchair, the world estimate is usually taken which puts the number of people needing wheelchairs in Uganda as a developing country at 6% of the total population. Uganda has a current population of about 25 million people. This means that Uganda may require as many as 1,500,000 wheelchairs to adequately meet the need.

Out of this need, it is estimated that only 1% has been met. In absolute terms therefore, Uganda has met only approximately 250,000 wheelchairs, leaving a gaping deficit of over 1,400,000 wheelchairs outstanding. It is also known that:

• Out of the wheelchairs in use, it is estimated that 75% are imported.

- The imported wheelchairs as stated by the users above, are usually unsuitable to the local terrain, generally lack spare parts and are difficult to maintain.
- Of the locally produced wheelchairs, only a few are produced specifically after an assessment of the user as highlighted by MADE, a producer of wheelchairs. The Director noted that: "Buyers order for mass production to be made and delivered without prior assessment. This is because in most cases the buyer of a wheelchair is not the user".<sup>13</sup>
- 100% of the wheelchairs in use were not provided as part of a systematic reverence of the rights of PWDs but were either personally procured or donated as a goodwill gesture.
- The production in many a workshop averages about 5 25 wheelchairs a year despite the apparent large need for wheelchairs. Concerning this contradiction between great need for wheelchairs and abnormally low orders placed to producers, the Workshop Manager in Katalemwa Cheshire Home noted that: *"Users are unable to purchase wheelchairs. Parents too do not visualize their children's' needs"*<sup>14</sup>

It is quite clear from the owners of workshops that there is need for wheelchairs but all that need is not demand. For the country to address the wheelchair situation meaningfully there is need to strengthen the demand for local production of wheelchairs through advocacy and the Wheelchair Fund.

# 4.4 Measures that should be put in place to ensure good and quality production of Wheelchairs

According to the wheelchair users who attended the Focussed Group Discussions,<sup>15</sup> and the Disability Leaders who responded to the Leaders' Questionnaire<sup>16</sup>, Government through the Ministry of Health and other wheelchair stakeholder Groups, should put in place regulatory policies, standards and guidelines that should be followed by wheelchair makers and should be enforced through the National Bureau of Standards (NBS), just like any other consumable products in the country. These production guidelines can be supervised by the National Wheelchair committee or by any other organ as Government may deem fit.

Government and the National Wheelchair Committee should also find a regulatory mechanism for ensuring the quality and appropriateness of wheelchairs that are imported, distributed and used in Uganda. These mechanisms are already

<sup>&</sup>lt;sup>13</sup> Director of MADE answering Question 12(a) of the Questionnaire to Workshops: What challenges do you face in producing wheelchairs?

<sup>&</sup>lt;sup>14</sup> Workshop Manager Katalemwa Cheshire Home answering Question 12(a) of the Questionnaire to Workshops: What challenges do you face in producing wheelchairs?

<sup>&</sup>lt;sup>15</sup> Analysis of Responses to Question 8 of the Focus Group Discussion: What do you feel is the Best way to improve local Production of wheelchairs?

<sup>&</sup>lt;sup>16</sup> Analysis of Responses to Question 7 of the Questionnaire to Disability Leaders: What do you think could bring about improved local Production?

available for a wide range of products especially those that relate to the health of citizens. Such a regulatory framework could be adopted and adapted to control and regulate the importation of wheelchairs as well.

In the short run however, Government and the National Wheelchair Committee should adopt the guidelines provided in *TATCOT Manuals*. TATCOT provides a series of Manuals that discuss the principles of wheelchair designs, Wheelchair prescription and wheelchair workshop safety.

The sponsors of wheelchairs and or their representatives should in some way be encouraged to deliver their donations to beneficiaries in person rather than send them. This will enable them to see for themselves the common mismatches that exist between the wheelchair supplied and the wheelchair needed including the endemic dangers of mass supply of generic wheelchairs.

The other measures that could be taken to ensure good and quality production of Wheelchairs could among others include:

- 1. Increasing the availability of trained wheelchair technicians by sending people to Tanzania for training on wheelchair Production and Maintenance. This would increase the availability of skilled personnel in wheelchair matters. When visiting the workshops it was quite clear that GYDA and MADE who had trained personnel understood the key issues about a quality wheelchair.
- 2. Employing those trained in Government workshops in the regions and districts as personnel to produce and or maintain wheelchairs on cost sharing basis;
- 3. Create an *Inspectorate of Wheelchair Production and Use (IWCPU*) in the Ministry of Health and staff it with qualified personnel with a mandate to:-
  - Regularly monitor both Public and Private Wheelchair manufacturing workshops to ensure adherence to production standards;
  - Regularly evaluate prescriptions for wheelchairs;
  - Take statistics on the status of the wheelchair in the country;
  - Inspect wheelchairs in use like it is done with weights and measures to ensure that the wheelchairs in use are assisting but not harming the users;
  - Do any such things as shall better the availability and use of quality wheelchairs.
- 4. Re-equip and modernize the existing public workshops so that they:
  - Can improve on designs e.g. Designing wheelchairs with carriages for luggage
  - Produce elegant and durable products
  - Reach out to PWDs in need of repair.

- 5. Encourage investment in wheelchair production by improving the business capacity of existing private wheelchair workshops by:
  - Improving production record keeping;
  - Facilitating them to acquire modern machinery and equipment under the micro-finance schemes;
  - Improving their business skills such as choosing appropriate materials, production scheduling, workshop safety and marketing;
  - Subsidizing local private producers.
- 6. Aid local community *Jua Kali* artisans to acquire skills in basic wheelchair maintenance;
- 7. Linking the medical and technical aspects of the wheelchair. For example, linking a physiotherapist's assessment to the technician's production;
- 8. Benchmarking the local workshops with other international producers of wheelchairs.
- 9. Sensitising the public on the rights of PWDs
- 10. Encourage the formation of village associations of wheelchair users so as to strengthen their efforts to get maintenance of their devices;
- 11. Improve the facilitation and use of the office of the District Rehabilitation Officer (DRO)

# 4.5 Wheelchair production in Uganda

### 4.5.1 Who produces wheel chairs in Uganda?

The wheelchairs produced locally in Uganda come from both public and private workshops. The Public Workshops are those owned by Government and usually located in Public Regional or National Referral Hospitals. Meanwhile private workshops are those that are owned by either NGOs or individuals for profit. The list of workshops producing wheelchairs is shown in **Appendix 8**.

# 4.5.2 Types of Wheelchairs produced in Uganda.

The workshops visited by the study team reported the production of different models and brands of wheelchairs. The table below shows the workshops visited and the kinds of wheelchairs they claim to be making or to have made.

No.	Name of Workshop Visited	Nearest	Type of Wheelchair in
INU.	Name of Workshop Visited	Town	production and Current status
1	Amuja's Workshop	Kabale	<ul> <li>3-wheeler Rigids</li> <li>Bicycle ambulances (<i>Produce on order</i>)</li> </ul>
2	Benedictine Metal Workshop - Tororo	Tororo	None     (Production Stopped)
3	Fort-Portal Regional Orthopaedic Workshop,	Fort-Portal	• None (Production Stopped)
4	FPD Workshop Kabale	Kabale	<ul> <li>Hacksteps,</li> <li>3-wheeler Rigids,</li> <li>Tricycles</li> <li>(No production in the last 2 years)</li> </ul>
5	Gulu Youth Development Association	Gulu	<ul> <li>Hackstep</li> <li>Four-wheeler Foldable,</li> <li>3-wheeler Rigids,</li> <li>Tricycles</li> <li>(Actively producing under a special project)</li> </ul>
6	Kabenhas Kabale	Kabale	<ul> <li>Hacksteps</li> <li>Tricycles.</li> <li>(Produced 12 last year on order)</li> </ul>
7	Katalemwa Cheshire Home	Kampala	<ul> <li>Hackstep,</li> <li>Four-Wheeler Foldables,</li> <li>3-wheeler Rigids,</li> <li>Tricycles</li> <li>(Actively in production under special management)</li> </ul>
8	MADE	Kampala	<ul> <li>Four-wheeler</li> <li>3-wheeler Rigids,</li> <li>Whirlwinds</li> <li>(In production)</li> </ul>
9	Masaka Vocational and Rehabilitation Centre	Masaka	Only a wheelchair distribution centre, not a production w/shop
10	Mbale Regional Orthopaedic Workshop	Mbale	<ul> <li>None</li> <li>(Production Stopped)</li> </ul>
11	Mbarara Regional Orthopaedic Workshop	Mbarara	Once assembled and distributed but has never produced
12	Mulago Orthopaedic Workshops	Kampala	<ul> <li>Hacksteps,</li> <li>Four-wheeler Foldables,</li> <li>Tricycles</li> <li>(<i>In production</i>)</li> </ul>
13	Ocoko Vocational and Rehabilitation Centre	Arua	• Tricycles ( <i>Not in production</i> )
14	St. Ludigo	Jinja	<ul> <li>Hacksteps,</li> <li>3-wheeler Rigids,</li> <li>Tricycles</li> <li>(<i>In production</i>)</li> </ul>

Table 6: Showing Workshops visited and the types of wheelchairs they produce
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From the responses of the disability leaders, a number of wheelchair models were said to be produced. The wheelchairs produced in Uganda according to the disability leaders were broadly categorised into:

- Tricycles
- Tricycles with carriages (specifically for trade.)
- Hucksteps (Kampala Wheelchair)
- 3-wheeler Rigids
- 4-wheeler Foldables
- Whirlwind
- Self Propelled Types
- For purposes of emergencies in transport to health facilities, there was a product called *"Bicycle Ambulance"* for the sick produced in Amuja's Workshop in Kabale. These are particularly for mountainous areas transportation.

Generally however, wheelchairs produced in Uganda can be categorised as:

- 1. Tricycles
- 2. Hucksteps (Kampala Wheelchair)
- 3. 3-wheeler Rigids
- 4. 4-wheeler Foldables
- 5. Whirlwinds
- 6. Self Propelled Types

# 4.5.3 Production versus demand for wheelchairs in Uganda

# Table 7: Showing the Production and sales of Wheelchairs in 2005

No.	Name of Workshop Visited	Nearest Town	No of Wheelchairs sold in 2005
1	Amuja's Workshop	Kabale	17
4	FPD Workshop Kabale	Kabale	No data captured
5	Gulu Youth Development Association	Gulu	130
6	Kabenhas Kabale	Kabale	30
7	Katalemwa Cheshire Home	Kampala	102
8	MADE	Kampala	80
12	Mulago Orthopaedic Workshops	Kampala	240
13	Ocoko Vocational and Rehabilitation Centre	Arua	13
14	St. Ludigo	Jinja	155

(Notta benne: This total production in each workshop is not consistent year after year. If compared to need, per district let alone the region served, this production levels are only a drop of fresh water in an ocean.)

### 4.5.4 Reasons for Low Production of Wheelchairs in Uganda

As already stated above, out of the wheelchairs in use in Uganda, it is estimated that 75% are not locally produced. It means that only 25% of the total number of wheelchairs in use in the country is locally produced. Several reasons were advanced by workshops visited for this situation.

No.	Name of Workshop Visited	Reasons for Low Production
1	Amuja's Workshop	<ul> <li>Low demand</li> <li>Competition from imported chairs</li> <li>Lack of capital and equipment</li> </ul>
2	FPD Workshop Kabale	<ul> <li>Lack of capital</li> <li>Lack of materials</li> <li>Limited marketing being done</li> <li>Lack of Skilled labour</li> <li>High cost of production</li> </ul>
3	Gulu Youth Development Association	<ul> <li>Slow growth in production capacity</li> <li>Lack of materials</li> <li>Limited skilled labour</li> <li>Cost of production</li> <li>Limited market.</li> </ul>
4	Kabenhas Kabale	<ul><li> Lack of capital</li><li> Limited marketing being done</li></ul>
5	Katalemwa Cheshire Home	<ul><li>Low demand</li><li>Competition from imported chairs</li><li>Skilled labour</li></ul>
6	MADE	<ul> <li>Lack of adequate capital</li> <li>Lack of materials</li> <li>Marketing problems</li> <li>High cost of production</li> <li>Limited market.</li> </ul>
7	Mulago Orthopaedic Workshops	• Demand is low
8	Ocoko Vocational and Rehabilitation Centre	<ul><li> Lack of capital</li><li> Lack of materials</li><li> Lack of Skilled labour</li></ul>
9	St. Ludigo	<ul><li> Low Demand</li><li> Limited market.</li></ul>

Table 8: Showing the reasons for low production in wheelchair-workshops visited

From the situation depicted by the table above, there is a severe contradiction between an overwhelming need for wheelchairs and workshops experiencing low demand. This is apparently because those who need the support of a wheelchair do not have their own means to acquire the device. They have to wait for or make appeals to someone else's goodwill to get a wheelchair.

The process of getting a suitable wheelchair is long and expensive. It usually should begin with assessment, design, materials ordering, fabrication, finishing, testing and then finally delivery. All these cost a toll beyond the wish and reach of many would-be wheelchair sponsors. As an alternative, wheelchair sponsors usually resort to mass orders and generic supply. Whereas this has a cost advantage to the sponsors, it should be recognised that it usually has a health disadvantage to the users.

Wheelchairs are a complex matter with some issues quite irreconcilable. For instance, they should be produced specifically for each individual to suit the individual's impairment. Though they must cost less, they should be made strong. They must be light, made to last long, yet remain cheap enough to be affordable. To find materials that suit this matrix can be and has been hard in the Ugandan environment.

There is limited link between the actual users and the producers of wheelchairs and worse still there is no basic and empirical statistics on which to base demand forecasts. Since most of the reliable wheelchair producers are private people who in addition to giving service are also profit oriented, investment into wheelchair production is low because of the anticipated low business turnover.

Coupled with these limitations is the lack of wheelchair production expertise (Human Resources). Many of the existing producers are only local artisans and welders who do not have adequate knowledge of the intricate wheelchair production. Arising from this fact, some of their products are technically faulty and have been abandoned. As a result, subsequent orders have in the same bearing reduced.

Arising from limited direct investment into wheelchair production, there is a deficiency in high efficiency production machinery, a factor which has led many producers in the country to depend on basic hand operated equipment which does not efficiently handle all matters of production. This aspect only feeds into strengthening the competitiveness of the imported wheelchairs.

As already said, the existing wheelchair producers are only local artisans and welders who do not have adequate knowledge in wheelchair production. They also lack other skills for business beyond production. It was quite obvious that important skills such as keeping production statistics, book-keeping, marketing, demand analysis, materials procurement, customer care, and even business administration were clearly absent.

A closer discussion showed that many of the local artisans like those in Kabale, picked interest in wheelchair production as a result of availability of district tenders to that end. Their business set ups were not to make wheelchairs. The District tender was just an opportunity to get quick business. They ordinarily base their income on other products other than wheelchairs and may not be interested

in focusing on improved production skills for wheelchairs after completion of the supply contracts with the districts.

In summary, the reasons for low wheelchair production in Uganda are:

- 1. Slow growth in the capacity of producers to match the demand.
- 2. Competition from imported chairs.
- 3. The process of getting a wheelchair is long.
- 4. Lack of capital and accessible capital markets in Uganda.
- 5. Lack of materials.
- 6. Limited marketing being done.
- 7. Lack of Skilled labour.
- 8. High cost of production
- 9. Limited market; PWDs want chairs but they cannot afford

### 4.5.5 Challenges of wheelchair producers in Uganda

Whereas there is an overwhelming need for wheelchairs, the principal challenge to wheelchair producers round the country is limited demand, i.e. luck of purchasing power among the consumers of the products. This is because those who need wheelchairs in most cases do not have their own means to acquire them. They have to wait for or make appeals to someone else's goodwill to get the chairs. In economics, the need for a product must combine with the ability to afford it to create demand. This factor is missing in most wheelchair users.

The limited demand for wheelchairs coupled with the usual need for sponsors, affects production planning because it is not easy to forecast when the next order will come.

An analysis of the challenges of wheelchair producers in Uganda brought forth a catalogue of challenges which was summarised as follows:

- 1. Lack of quality control guidelines
- 2. Low demand from users
- 3. Wheelchair market is not a fast growing market
- 4. Wheelchair production requires a lot of electricity which is always not available
- 5. Poor equipment base, especially pipe bending machines
- 6. Marketing the products is a problem
- 7. The cost of inputs is high
- 8. Caster wheels are hard to come by
- 9. There is no skills' upgrading centre in Uganda for wheelchair producers. The nearest is in Tanzania
- 10. Capital for investment is limited or lacking
- 11. Records management is a problem too i.e. Book-keeping, Stores records, maintenance records, costing, ordering and production records

# **4.5.6** How the Wheelchair Producers wish to be assisted through the Wheelchair Fund

In the questionnaire to Wheelchair workshops, there was a question inquiring how the Wheelchair Fund should aid wheelchair producing workshops. An analysis of the various responses to that question showed that the workshops wanted help in the following areas:

- Capitalization of their businesses
- Location of quality materials
- Location and acquisition of appropriate equipment
- Establishment of a training facility for wheelchair production
- Skills Development and capacity building in wheelchair production
- Business skills such as marketing, book-keeping, costing, and management
- Construction of workshops

### 4.5.7 Wheelchairs most suited to the Local Environment

There are nine different types of wheelchairs in use in Uganda according to the survey findings. The prevalence of the use of these wheelchairs as shown in the table below is also an indicator of the suitability of the wheelchairs in the local environment.

No.	Wheelchair Type	Prevalence in
		%
1	Tricycles and Non-Foldable wheelchairs	53%
2	Hucksteps (Kampala Wheelchair)	31%
3	3-wheeler Rigids	6%
4	4-wheeler Foldables	6%
5	Whirlwind	1%
6	Other Foldables	2%
7	Self Propelled Type	1%
8	Motorized wheelchairs	1%

According to the respondents in the survey, the wheelchairs most suited to the environment were ranked as follows:

- The tricycle was considered the most suitable because it suits both the rural and urban environments and can be adapted to carry luggage, a condition very vital for petty disabled traders.
- The second most suitable wheelchair was the Huckstep (Kampala Wheelchair). It is fairly strong but it is a largely an outdoor devise because its size limits its manoeuvrability through doorways and narrow village paths.
- The 3-wheeler rigid is more appropriate in the rural dwellings
- Meanwhile the 4-wheeler foldable is more suited for the urban setting where there are smoother roads.

• The motorised wheelchair is excellent in comfort and manoeuvrability but can only work where there is regular supply of electricity to re-charge batteries and where there are no pot-holes. Therefore it is completely ruled out of the rural areas where there is no electricity and village paths are rough and sometimes muddy. Even in the urban setting, its use is limited to the more developed areas of towns.

### 4.5.8 Technology currently used in wheelchair production in Uganda

All workshops visited by the study team and were in production, currently use simple hand driven pipe bending and welding machines as the key machinery in production. The other equipment is hand tools. There is no automation and electronic testing of production quality, such as wheel alignment, centrality of the trailer caster wheel, the uniformity of cushioning and all such technical matters in a wheelchair. It seemed that only MADE, Mulago and GYDA had an idea that a wheelchair is prescribed. The rest just assumed that a wheelchair is a wheelchair and that is it.

### 4.5.9 Who provides the wheelchairs used in Uganda?

Wheelchairs used in Uganda are derived from various sources. According to the survey, the wheelchairs are provided by mainly DPOs, NGOs, Churches and Local Governments. The analysis of the responses on the providers of wheelchairs showed this position:

No	Source of Wheelchairs	Number of Respondents acknowledging the source	Percentage acknowledgement of the source
1	DPOs	28	31.5
2	Churches	16	18.0
3	ADD	3	3.4
4	NGOs	7	7.9
5	Shared Blessings	2	2.2
6	Local Governments	6	6.7
7	Rotary Clubs	3	3.4
8	МоН	1	1.1
9	Cultural Leaders	2	2.2
10	Politicians	2	2.2
11	Other miscellaneous sources	19	22.4
	Total	89	100.0

Table 10: Showing the Sponsors/providers of wheelchair used in Uganda

This analysis provides a pointer on who pays for the wheelchairs used in the country. These various sources lobby for, buy or import wheelchairs using their own mechanisms and finances, and distribute them to beneficiaries of their choice.

However, apparently none of them makes provision for training and adapting the users to use the chairs and how the devices they provide are to be maintained.

The wide ranging sources of providers are indicative of the fact that no single body has so far taken responsibility for the supervision of the provision of the much needed appliance. This is a sad story and greatly deters development of the users, and even exposes them to dangers posed by unsuitable appliances.

Ideally government should be responsible for the supervision of production subsidization, production and distribution of the vital mobility appliances. The current position of only 1% out of all those in need of wheelchairs being able to access them is insufficient and unacceptable.

On the other hand, the high prevalence of DPOs being acknowledged as the main source of wheelchairs is an indication of the efforts PWDs are making to address their own challenges. This should not be construed to mean self-sufficiency, but rather as an indicator of some level of growth in the disability movement in standing up to confront their challenges.

# **4.5.10** The extent of Wheelchair Producers' knowledge of the requirements for and the minimum standards of wheelchair production

Currently, there are no requirements, or set of minimum standards that wheelchair producers are demanded to follow in the manufacture of wheelchairs in Uganda. Similarly there also no guidelines, standards or catalogue of requirements that wheelchair importers are required to observe in introducing any wheelchairs into the Country. As such, wheelchair producers in Uganda do not follow any standards or requirements because there are none.

The matter of minimum standards and requirements to be observed in making or importing wheelchairs is a matter of acute gravity. If the concept of a quality wheelchair is to be introduced and upheld in Uganda, then some minimum standards have to be introduced, inculcated to all wheelchair stakeholders and enforced through a specific organ of Government.

Some wheelchair producing workshops visited, proposed the aspects hereunder as requiring specific standards or at least a regulatory framework:

- Prescription
- Weight
- Alignment
- Movement
- Training and adaptation of users
- Technical Measurements
- Workshop standards such as:
  - Minimum equipment base
  - Existence of trained personnel

Use of some basic standard materials with a definite minimum quality

# 4.6 Wheelchair procurement procedures and quality assurance in procurement

Apart from Local Governments, the other providers of wheelchairs do not have any rigid procurement procedures for wheelchairs. In DPOs, Churches, NGOs, Rotary Clubs etc, a decision to procure wheelchairs is reached usually in meetings of the governance bodies of those organizations, then a supplier is identified, orders are issued, payments effected, then with conspicuous ceremony, the wheelchairs are distributed to beneficiaries on the principle of *"take one for yourself, not take one suited to you"* 

Politicians too follow almost the same process. They make pledges to provide wheelchairs, go out to identify a supplier, make orders, bring the wheelchairs and distribute them in their name on the same principle.

In Local Governments, a need for wheelchairs is identified by a community; the need is forwarded to the Sub-County for onward transmission to the District Procurement Committee in accordance to the Public Procurement and Disposal of Public Assets Act 2003. (PPDPAA). A tender is advised and firms who feel they can fulfil the tender requirements submit bids to supply the chairs. One competitive bidder is chosen and generically provides the chairs to the Sub-County authorities for transmission the users.

In all the procurement procedures above, there is little or no mention of assessment of the user, quality assurance or suitability of the chair to the user's impairment. This apparent neglect of important issues in the provision of wheelchairs is due to ignorance and the absence of wheelchair experts in the Health/rehabilitation Delivery Systems in the Districts.

# 4.7 The impact of the current wheelchair chain of procurement on the users

The current modes of provision of wheelchairs have some effects on the users. Some are positive and others are negative and even dangerous to lives of the wheelchair users.

- 4.7.1 Positive effects
  - These methods have been used to provide wheelchairs to beneficiaries who did not have an iota of where to get a wheelchair, even a bad one. On the principle of *"something is better than nothing"*, there were some wheelchairs in the community.
  - The presence of these wheelchairs in the community even if they were unassessed and generic, woke up communities to the need for wheelchairs to improve the lives of some of the community members.

### 4.7.2 Negative effects

- Discomfort to the user because of unfitting dimensions;
- Possibility of secondary disabilities to users;
- Physical bodily harm such as pressure sores;
- Abandonment of the wheelchair, when it proves too unsuitable, which is waste and
- Reversion to the life of crawling despite the presence of a wheelchair, which implies that the problem was not solved after all.

# 4.8 Challenges faced by wheelchair users

Wheelchair users meet a lot of challenges in the course of their day to day lives. These challenges can be categorised into Technical, Community ignorance, and personal challenges.

# 4.8.1 Technical challenges.

These are challenges faced by wheelchair users arising from the design and structure of the wheelchairs, including problems of maintenance. They include but may not be limited to:

- Un-assessed wheelchairs lead to discomfort and possible secondary disability;
- Inability to independently afford a wheelchair of ones' choice;
- High cost of wheelchairs maintenance;
- Lack of appropriate spare-parts for wheelchairs;
- Some chairs are built with weak materials, which reduces their carrying capacity;
- Imported wheelchairs are brought without a provision for spare-parts;
- Wheelchairs especially Tri-Cycles require many components that make them expensive to maintain;
- Lack of demand driven innovations for wheelchairs that suits the environment;
- An impossibly rough terrain (such as mud, potholes, deep sand, hills, sharp stones) that leads to constant breaking down of the chairs.

# 4.8.2 Challenges arising from Community ignorance

These are challenges faced by wheelchair users arising from community, Governments, and wheelchair donors' ignorance of basic wheelchair aspects and principles of a quality Wheelchair, as well as the rights of the users. In this area the challenges include:

• Poor road designs that do not consider the needs of wheelchair users

- Fear of being run over by vehicles because drivers are not sensitive to the road needs of wheelchair users. (For instance, they hoot loudly and ride past menacingly fast );
- Inaccessible buildings;
- Lack of easily accessible skilled service providers for wheelchair maintenance;
- Public transport is double costly especially with Unfoldables;
- Wheelchairs are not regarded as part of the Human Rights of the users;
- There are no approved arrangements by Government, DPOs, or Local Governments for maintenance of wheelchairs;
- Wheelchairs are viewed as mechanical and not orthopaedic equipment.

# 4.8.3 Personal challenges.

These are challenges faced by wheelchair users arising from the weaknesses their impairments have caused as well as personal perceptions which are usually expressed by poor self perception and compromised self esteem. The challenges here include:

- Hilly/ mountainous terrain is a challenge especially to children and women wheelchair users, for independent movement
- Poverty leads to inability to maintain wheelchairs and to have an independent choice of a desired wheelchair.
- Need for helpers to push the chairs up hill limits independence
- Mud during the rainy season presents a new set of challenges
- Dependency syndrome among PWPDs, (little creativity and innovation).
- Wheelchair users do not have a common forum to voice their concerns because of their ignorance of their rights and difficulty in mobilising them to come together
- The current disability leaders too have not had a proper grasp of what a quality wheelchair is. Thereby they cannot present and represent the users' needs accurately.

# 4.9 Mitigation measures for Challenges faced by wheelchair users

The Focus Group Discussions proposed the measures below as possible mitigating measures for the challenges faced by wheelchair users in the country.

• Users should come together in each area and identify some artisans whose skills can be improved in wheelchair maintenance through the Wheelchair Fund;

- Wheelchair users should associate, pool their resources for repairs and create a community scheme for wheelchair maintenance;
- A lot of sensitization work should be done to wheelchair users, Disability leaders, Civil Society Leaders such as Rotarians, Ministry of Works' personnel, District and Sub-County Officials, District Health Personnel, District Engineering Personnel, Local Councils, Parliament and bodies representing motorists on the rights of People using wheelchairs. Each sensitization mission should target a specific aspect relating to the targeted persons' role in making wheelchair use conducive in every environment;
- Research should continue on wheelchairs with the objective of making wheelchair use easier and more independent.
- Assessment of users before providing wheelchairs should be emphasised as part of Health Service Delivery System Standards
- Local Councils should provide space in their Health Service Systems for maintenance of Wheelchairs

# 5.0 CONCLUSIONS AND RECOMMENDATIONS

# 5.1 Conclusions derived from the findings (The status of the Wheelchair in Uganda)

A wheel chair is an assistive device which is ideally meant to support locomotion for persons who have temporarily or permanently failed to sustain free and unsupported movement on their own, either arising from ill health, permanent disability, advanced age or a combination of these factors. It is supposed to be part of the human rights of the user, and an orthopaedic device. Nevertheless, it is rarely viewed as such. Many a time, a wheelchair is seen in the light of a mechanical devise, a "*bicycle*" for a person with a disability and kind of luxury.

The wheelchair in Uganda has not had a policy, a regulatory framework or any supervision from any quarter, Governmental or otherwise. Thereby the provision and use of wheelchairs in Uganda has just been random. This has of course had a hard bearing on the users.

In describing the state of wheelchairs that users came along with to the Focus Group Discussions, a study team member wrote that;

"Most of the wheelchairs that assembled for the meetings were largely pieces of frame and tyres. Small uneven flaps of plywood darkened with overuse made up the remains of the wheelchairs. The cushions were long gone leaving the wooden base exposed. The few that had cushions had shapeless torn dark pieces of sponge weighed down with old age.

The iron frames had long lost their original colour, which could be detected only as old patches of exhausted paint in the less used parts of the frame. The most used parts exuded a silvery shine. On the whole, these wheelchairs were very old and ill maintained. For beauty they do not pass. Yet these pieces of iron and wood are so crucial to the owners, their closest friends, with a partnership no one can break"<sup>17</sup>

There is no reliable data on the exact, or even the approximate number of people in Uganda who need the support of a wheelchair as a mobility device. However close observation and scrutiny of the Disability Leaders' comments, clearly points out to the fact that the need for wheelchairs is empirically large and only a small fraction of that need is met.

The provision of wheelchairs in Uganda is currently done as a matter of expression of goodwill but not as part of observance of the Human Rights of the beneficiaries as citizens. As such most wheelchairs provided are donations, un-assessed and un-adapted to the users' impairments.

Over 75% of the wheelchairs in use in Uganda are imported. These imported wheelchairs, despite their comfort and beauty, are difficult to maintain and generally lack spare parts. There is need to strengthen local production and

<sup>&</sup>lt;sup>17</sup> Mary Mukisa – The state of wheelchairs that users came along with to the Focus Group Discussions

maintenance of wheelchairs including addressing the technological base used by wheelchair makers.

### 5.2 Recommendations

1. Wheelchairs should be taken as part of the human rights of the users and a campaign to this effect should be effected at all levels. A wheelchair in this regard should be treated as a right to decent living, physical mobility, social independence and a chosen lifestyle. Therefore government involvement should be clearly stated and emphasized.

All the DPOs involved in wheelchair distribution should work closely with the users in the advocacy campaign to get government take on responsibility for wheelchair users as its citizens with needs and rights just like any other citizens usually referred to as *"normal"*.

- 2. A wheelchair should bear attributes that contribute to its definition as an assistive or orthopaedic device. These attributes and concept of a quality wheelchair should officially be supervised under and as part of the Health Service Delivery System. To effect this, there has to be a Government sponsored *policy*, *Law*, *or some Regulatory Framework* for the management of wheelchair affairs.
- 3. In the short run however, Government and the National Wheelchair Committee should adopt and or adapt the guidelines provided in *TATCOT Manuals.* TATCOT provides a series of Manuals that discuss the principles of wheelchair designs, Wheelchair prescription and wheelchair workshop safety.
- 4. There is need to strengthen local production and maintenance of wheelchairs including addressing the technological base used by wheelchair makers to ensure production of quality wheelchairs. The interventions should include subsidising those workshops that have trained personnel to improve production, develop their business acumen and build their management capacity.
- 5. Follow up programmes and mechanisms should be instituted on all wheelchairs distributed to assess their assistiveness and maintenance challenges if any.
- 6. The other measures that could be taken to ensure good and quality production of Wheelchairs could include those described in Part 4.4 of this report.
- 7. There is need for the National Bureau of statistics to conduct a detailed survey on mobility assistive devises using discrete instruments of data capture that should first be shared and pre-tested with the involvement of all Physical disability stakeholders so as to establish a reliable data base for planning wheelchair provision as a right to the users.

- 8. A lot of sensitization work should be done to wheelchair users, Disability leaders, Civil Society Leaders such as Rotarians, Ministry of Works' personnel, District and Sub-County Officials, District Health Personnel, District Engineering Personnel, Local Councils, Parliament and bodies representing motorists on the rights of People using wheelchairs. Each sensitization mission should target a specific aspect relating to the targeted persons' role in making wheelchair use conducive in every environment.
- 9. Research should continue on wheelchairs with an objective to make wheelchair use easier, comfortable, safe and more independent.
- 10. DPOs should promote the creation of mechanisms or fora that encourage wheelchair users getting together to voice their challenges. Such fora should enable wheelchair owners to lead the struggle for their own good.
- 11. DPOs and the NWC should advocate for the revival of the old government strategy of Sub-counties and Districts providing/subsidising the maintenance of wheelchairs for their residents.
- 12. DPOs and the NWC should advocate for a wider range of communitybased/ civil society organisations to address wheelchairs as a fundamental need for the users. Faith -based organisations are an example that if well mobilised would be in good position to promote wheelchair availability for their members.

# APPENDICES

#### **APPENDIX 1**

No.	Central Region	No.	Eastern Region	No.	Northern Region	No.	Western Region
1	Kayunga	1	Bugiri	1	Gulu	1	Bushenyi
2	Kiboga	2	Busia	2	Kitgum	2	Bundibugyo
3	Luwero	3	Jinja	3	Lira	3	Mbarara
4	Masaka	4	Kamuli	4	Nebbi	4	Ntungamo
5	Rakai	5	Kapchorwa	5	Pader	5	Kanungu
6	Wakiso	6	Mbale	6	Arua	6	Kabale
7	Mubende	7	Mayuge	7	Yumbe	7	Kasese
8	Kampala	8	Pallisa			8	Kyenjojo
9	Kalangala	10	Sironko			9	Kabarole
		9	Soroti			10	Masindi
		11	Tororo				
	TOTAL NUMBER OF DISTRICTS WHERE THE STUDY WAS DONE				37		

# LIST OF DISTRICTS WHERE THE STUDY WAS CONDUCTED

#### **APPENDIX 2**

# LIST OF PARTICIPANTS IN FOCUS GROUP DISCUSSIONS

	KABALE FOCUS GROUP DISCUSSION	KIREKA FOCUS GROUP DISCUSSION	GULU FOCUS GROUP DISCUSSION	SOROTI FOCUS GROUP DISCUSSION
1	Byamukama E.	Kanyunyuzi Florence	Achen Florence	Abaru James
2	Byamukama Ray	Namukasa Jane Frances	Akello Margaret	Alum Jane
3	Habassa Winfred	Obbo Stephen	Akumu Josephine	Amenya Teopista
4	Kanesanju Elinathan	Ssebaggala John	Atim Esther	Apolot Juliet
5	Katushabe Prudence	Yamuleme Yokana	Komaketch Donato	Asio Florence
6	Kemerwa Onani		Laker Mary	Elangot Andrew
7	Kiconco Barbara		Odong Francis	Enyongu Thomas
8	Kobusingye Anne		Olyel Jacob	Esaete Bibiana
9	Mbaasa J.		Omona Richard	Ikiror Hellen
10	Mpairwe E		Omony Patrick	Ocelep Isimail
11	Naluyamba Ruth		Opwonya Stephen	Okello Alfred
12	Niwagaba Fred		Oweka Iture	Olila Yunusu
13	Nyakunyumbu Karooli		Oyella Victoria	Ongwara Micheal
14	Rutacengyerwa Emmanuel		Ojok Patrick	
15	Tugume F.			
# IMPORTANT DATES IN THE DEVELOPMENT OF A WHEELCHAIR

# The History of Wheelchairs

- 6th century this is the earliest date in which an image of a wheelchair was found. It was incised in stone on a Chinese sarcophagus.
- 16th century King Philip II of Spain used an elaborate rolling chair with movable arm and leg rests.
- 1700 King Louis XIV used a "Roulette" for moving about while recovering from an operation.
- 18th century the first wheelchair that resembles today's design was found. It had two large front wooden wheels and one caster in rear.
- 19th and 20th centuries following the American Civil war and World War I, the first wheelchairs were built *en mass*, with wooden frames, wicker seats, adjustable arm rests, footrests, and large spoked wheels.
- 1894 A U.S. patent was filed for a wheelchair with a fixed frame, adjustable surfaces, firm wicker seats, and large rear wheels for self-propulsion.
- 1932 Herbert Everest (an injured mining engineer) and Harold Jennings (a mechanical engineer) collaborated to design the first folding frame wheelchair. They went on to form the company that is today known as Everest & Jennings or E&J.
- 1937 A patent was filed for the x-folding frame wheelchair. Sam Duke also marketed a folding wheelchair at same time.
- 1950s Everest & Jennings developed the first powered wheelchair. They followed the development of transistor-controlled motors and adapted it to their interest by adding a motor to their manual wheelchair design,
- 1952 The beginning of wheelchair sports occurred with the first games held at the Stoke Mandeville Rehabilitation Centre in England.
- 1964 The first Para-Olympics games using wheelchairs were held in Tokyo, Japan.
- 1975 Bob Hall competed in Boston Marathon using a wheelchair (26miles on a wheelchair).
- 1970/80 revolution in lighter weight manual chairs driven by the need and desires of wheelchair athletes.
- 1980s microprocessor-controlled powered wheelchairs were developed, which allowed customization of controls to meet more user needs.

• 1980-90s - the revolution in powered wheelchair design, control, styles, range or travel distance, suspension, manoeuvrability, seating and other user options.

### Sources:

- How to Select and Use Manual Wheelchairs, by A. Bennett Wilson, Jr., Rehabilitation Press, Box 380, Topping, VA. 1992. ISBN: 1-880902-04-4
- Lecture at the International Seating Symposium "Wheeling in the New Millennium" by Dr. Bonita Sawatsky, Department of Orthopaedics, BC Children's Hospital, Vancouver, BC, Canada V6H 3V4.
- This <u>lecture on the history of wheelchairs</u> is now on WheelchairNet. <../../WCN\_WCU/SlideLectures/Sawatzky/WC\_history.html>

# LIST OF WHEELCHAIR WORKSHOPS VISITED

No.	Name of Workshop Visited	Region	Nearest Town	Production status at the time of visit
1.	Amuja's Worksop - Kabale	Western	Kabale	Producing
2.	Benedictine Metal Workshop, Tororo	Eastern	Tororo	Not Producing
3.	Fort-Portal Regional Referral Hospital, Buhinga	Western	Fort- Portal	Not Producing
4.	FPD Kabale	Western	Kabale	Produced 2 years a go
5.	Gulu Youth Development Association (GYDA)	Northern	Gulu	Producing
6.	Kabenhas - Kabale	Western	Kabale	Producing
7.	Katalema Cheshire Home	Central	Kampala	Producing
8.	MADE	Central	Kampala	Producing
9.	Masaka Vocational & Rehabilitation Centre	Central	Masaka	Has never Produced
10.	Mbale Regional Referral Hospital	Eastern	Mbale	Producing
11.	Mbarara Regional Workshop	Western	Mbarara	Not Producing
12.	Mulago Orthopaedic Workshop	Central	Kampala	Producing
13.	Ochoco Vocational & Rehabilitation Centre	Northern	Arua	Not Producing
14.	St Lugido	Eastern	Jinja	Producing

# Questionnaire on wheelchair production and *usage* administered on District leaders and councillors for persons with disabilities:

# Questionnaire on wheelchair production and usage answered by District leaders and councillors for persons with disabilities:

Dear friend,

Uganda National Action on Physical Disability (UNAPD) together with Ministry of Health-Disability Prevention and Rehabilitation (DPAR) section, have embarked on a survey to find out about wheelchair production in Uganda. The aim of the survey is to analyse local production of wheelchairs, their affordability, availability and usage in Uganda. As a leader and well informed person in the district I wish to request your participation in the survey by answering a few questions below. This information we are trying to gather is going to be put into proper use for the betterment of wheel chair production as regards quality and affordability.

I wish to assure you of full confidentiality and that this information shall be used appropriately for the purpose of improving the welfare of wheelchair users.

Thank you for your cooperation.

### Mary Mukisa

For the Wheelchair Fund Committee.

1)	District:			
ii)	Position of res	pondent		
iii)	Contact addre	SS		
	Telephone:			
	Postal addres	3S		
	E-mail			
	Physical addr	'ess		
2)	Do you know an	y workshop /anybody pr	oducing w	heelchairs in your district or region?
	Yes		No	
		(If no, go to g	uestion 7)	

h) If yes, give the details

		District
Name		
Addre		
Telepł		
What	type of	Wheelchairs do they produce?
	ii)	Approximately how many wheelchairs are produced:
		a) Per month? b) per year
	iii)	(a) If only a few are produced, why?
		(b) If many are produced, why?
	iv)	On average, what is the cost of one wheel chair?
3)		
0)		
	i)	Approximately, how many wheelchair users do you have in a district?
	ii)	Approximately, how many people use these locally produced wheelchairs?
	iii)	What makes other wheel chair users not to make use of the locally produced wheel chairs?

a)	In your view, are the wheelchair users satisfied with the quality of the locally produced
	wheelchairs?

	Yes 🗆	No	
Explain			
b)	Where would they wa	nt improvement	to be?
Other tha	n the locally produced v	vheelchairs, do	you have any other source of wheelchairs?
Yes ⊏	1	No 🗖	
i) If ye	s what are the sources	?	
•			
* *			
•			
ii) C	On average how many d	o you get from	those sources and how often?

4)

Source	No of wheel chairs	When/Frequency

iii)	What is the average price per wheelchair?	Unit cost
•		
٠		
•		

iv) Can you provide us the contacts of the above source of wheelchairs?

Supplier o	f wheelchairs	Address,	Telephone
5) Does	s your district or regional orth	nopaedic workshop produce wl	neelchairs?
Y	es 🗆 No 🗖		
6) Expla	ain why it manages to produ	ce or fails to	
i)	Does it repair?	Yes 🗆 No	
ii)	Where else are the wheeld	hairs repaired from?	

7) What do you think could bring about improved local production?

Thank you very much.

\_\_\_\_\_

\_\_\_\_\_

# Questionnaire on wheelchair production and usage For Orthopaedic Workshops:

# Questionnaire on wheelchair production and usage For Orthopaedic Workshops:

#### Dear Partner,

Uganda National Action on Physical Disability (UNAPD) together with Ministry of Health-Disability Prevention and Rehabilitation (DPAR) section, have embarked on a survey to find out about wheelchair production in Uganda. The aim of the survey is to analyse local production of wheelchairs, their affordability, availability and usage in Uganda. As a leader and well informed person in the district I wish to request your participation in the survey by answering a few questions below. This information we are trying to gather is going to be put into proper use for the betterment of wheel chair production as regards quality and affordability.

I wish to assure you of full confidentiality and that this information shall be used appropriately for the purpose of improving the welfare of wheelchair users.

Thank you for your cooperation.

### Mary Mukisa For the Wheelchair Fund Committee.

1)	Name of the Orthopaedic Workshop:
2)	Fitle of respondent:
2)	Does your workshop produce wheelchairs?
	Yes         No         (If No go to 8)
3)	If yes, what wheelchair designs do you produce? (Tick appropriate boxes)
	Hack step Four-Wheeler (Foldable)
	3-wheeler rigid Tricycles
4)	On average, how many does the workshop produce in a month?
5)	What is the cost of one wheelchair?
	70

Type of Wheelchair	Number produced per month	Cost of each wheelchair
Hacstep		
Four-Wheeler (Foldable)		
3-wheeler rigid		
Tricycles		

6) Approximately, how many wheelchairs do you sell out per year, and to who/which Districts?

Who/ District	No. of Wheelchairs sold per year

7) Why do you produce only that much?

\_\_\_\_\_

\_\_\_\_\_

-----

8) Do you know any other workshop in your region that produces wheelchairs?

------

9) If you do not produce wheelchairs, where do you get them from, for your clients and at how much?

-----

10) What types are you able to acquire, from which supplier and at how much does each wheelchair cost?

Supplier	Туре	Unit cost

11) Which type of the above mentioned designs is most appropriate to the environment?

12)	Where do you get the raw materials that you use?
13)	What do you consider a good quality wheelchair to be?
14)	What measures do you have in place to ensure that you produce good quality?
15)	Do you get any external funding other than profits? s No
16)	If yes, from who? 1

	2
	3
17)	What strategies have you put in place to improve marketing of your produce?
11).	Do you have a system for records management? Yes No
Expl	ain
12.)	What Challenges do you face:
	a.) In producing wheelchairs?
	b.) In management of the workshop?
13.)	What challenges do wheelchair users face in accessing the wheelchairs you produce?
14.)	How would you like the Wheelchair Fund to support you?

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15.) Anything else you would like to say about wheelchairs in your district?

Thank you!

# FOCUSED GROUP DISCUSSION GUIDE

- 1. How did you get your wheelchair?
  - a. How many wheelchairs do you have?
  - b. When did you start using a wheelchair?
- 2. How has the wheelchairs improved your life?
- 3. Supposing you did not have a wheelchair, what difference would it make?
- 4. What challenges do you face in using a wheelchair?
- 5. How do you address the challenge of repair and maintenance of your wheelchair?
- 6. How do you compare locally produced wheelchairs and the imported ones?
- 7. Is there any kind of system or scheme that can be put in place to encourage communal maintenance and repair of wheelchairs?
- 8. What do you feel is the best way of Improving local production of wheelchairs?
- 9. What is your opinion about paying for the wheelchairs?
- 10. Anything else you would like discussed about wheelchairs?

#### APPENDIX 8 LIST OF WORKSHOPS PRODUCING WHEELCHAIRS IN UGANDA

- Name of Workshop KAWADISA Mubende Rehabilitation Centre Nearest Town – Mubende District – Mubende Region - Central Postal Address - No information available Physical Address - KAWADISA Market Public or Private Ownership - Private Proprietor - KAWADISA, a local Association of war causalities Soldiers Telephone Contact – C/O Annet Bananura 0772 647 297 Type of Wheelchair Produced - Tricycles and Non-Foldable wheelchairs How long has the workshop operated - No information available Currently operational – Yes Market are covered by this workshop - No information available
- 2. Name of Workshop Mulago Orthopaedic Workshop Nearest Town -Kampala District Kampala -Region -Central Postal Address – No information Available Physical Address – Mulago Hospital Kampala Public or Private Ownership - Public Government of Uganda Proprietor -**Telephone Contact -Type of Wheelchair Produced –** Hackstep and Tricycles How long has the workshop operated – over 40 years **Currently operational** - Yes Market are covered by this workshop - No information available
- Name of Workshop Katalemwa Cheshire Home Nearest Town - Kampala District - Wakiso Region - Central Postal Address – No information available Physical Address - No information available Public or Private Ownership - Private Proprietor - No information available Telephone Contact – No information available Type of Wheelchair Produced – Tricycles, Foldables and Whirlwinds How long has the workshop operated – No information available Currently operational – Yes Market are covered by this workshop - No information available

- 4. Name of Workshop Ludigo Technical Workshop Nearest Town - Jinja District – Jinja Region - Eastern Postal Address - P.O Box 915 Jinja Physical Address - Spire Road Public or Private Ownership - Private Proprietor - No information available Telephone Contact – No information available Type of Wheelchair Produced – Tricycles and Ri-Wheelchair How long has the workshop operated - No information available Currently operational - Yes Market are covered by this workshop - No information available
- 5. Name of Workshop Mbale Hospital Nearest Town - Mbale District - Mbale Region - Eastern Postal Address - No information available Physical Address - No information available Public or Private Ownership - Public Proprietor - Government of Uganda Telephone Contact - No information available Type of Wheelchair Produced - Tricycles How long has the workshop operated - No information available Currently operational - Yes Market are covered by this workshop - No information available
- 6. Name of Workshop Bulangira Nearest Town - Pallisa District - Pallisa Region - Eastern Postal Address - No information available Physical Address - No information available Public or Private Ownership - Private- NGO Proprietor - No information available Telephone Contact - No information available Type of Wheelchair Produced - Tricycles How long has the workshop operated – No information available Currently operational - No Market are covered by this workshop - No information available

- 7. Name of Workshop Lilian Foundation Nearest Town - Jinja District - Jinja Region - Eastern Postal Address - No information available Physical Address - No information available Public or Private Ownership - Private Proprietor - No information available Telephone Contact - No information available Type of Wheelchair Produced – Tricycles, Hacksteps How long has the workshop operated - No information available Currently operational - No information available Market are covered by this workshop - No information available
- 8. Name of Workshop Soroti Catholic Diocese Development Organization (SOCADIDO) Nearest Town - Soroti District - Soroti Region - Eastern Postal Address - No information available Physical Address - Serere Road Public or Private Ownership - Private - NGO Proprietor - Soroti Catholic Diocese Telephone Contact - No information available Type of Wheelchair Produced - Tricycles How long has the workshop operated - No information available Currently operational - No information available Market are covered by this workshop - No information available
- 9. Name of Workshop FPD Orthopaedic Workshop Nearest Town - Kabale District - Kabale Region - Western Postal Address - No information available Physical Address - No information available Public or Private Ownership - Private -NGO Proprietor - Foundation for People with Disability (FPD) Telephone Contact - No information available Type of Wheelchair Produced – Hacksteps, Tricycles How long has the workshop operated - No information available Currently operational – Yes Market are covered by this workshop - No information available

- 10. Name of Workshop Amuja Metal Workshop Nearest Town - Kabale District – Kabale Region – Western Postal Address - No information available Physical Address – Mbarara Road Public or Private Ownership - Private Proprietor - No information available Telephone Contact - No information available Type of Wheelchair Produced - Hacksteps, Tricycles How long has the workshop operated - No information available Currently operational – Yes Market are covered by this workshop - No information available
- 11. Name of Workshop Mbarara Regional Orthopaedic Workshop Nearest Town - Mbarara District - Mbarara Region - Mbarara Postal Address - No information available Physical Address - No information available Public or Private Ownership - Public Proprietor - Government of Uganda Telephone Contact - No information available Type of Wheelchair Produced – Unfoldable, Tricycles How long has the workshop operated - No information available Currently operational – NO, It has never produced, but once only assembled Market are covered by this workshop - No information available
- 12. Name of Workshop Metrica Orthopaedic Workshop

Nearest Town - Lira District – Lira Region - Northern Postal Address – P.O Box 346 Lira Physical Address - No information available Public or Private Ownership - Private Proprietor - Ocan David (ochandavidwalter@yahoo.com) Telephone Contact – 0772 686 431 Type of Wheelchair Produced – Tricycles, Self Propelled Type How long has the workshop operated - No information available Currently operational - Yes Market are covered by this workshop - No information available

- 13. Name of Workshop Gulu Youth Development Agency Nearest Town - Gulu District - Gulu Region - Northern Postal Address - No information available Physical Address - No information available Public or Private Ownership - Private Proprietor - No information available Telephone Contact - No information available Type of Wheelchair Produced – Tricycles, Foldables, 3-Wheeler Rigid, and another one which the wheels can be pulled out, Modernized Wheelchair, How long has the workshop operated - No information available Currently operational - Yes Market are covered by this workshop - No information available
- 14. Name of Workshop Gulu AVSI workshop Nearest Town - Gulu District - Gulu Region - Northern Postal Address - No information available Physical Address - No information available Public or Private Ownership – Private - NGO Proprietor - No information available Telephone Contact - No information available Type of Wheelchair Produced – Unfoldables (Rigid), 3-wheeler Rigids, Tricycles How long has the workshop operated - No information available Currently operational - No information available Market are covered by this workshop - No information available
- 15. Name of Workshop Lukaya

Nearest Town - Lukaya District - Masaka Region - Central Postal Address - No information available Physical Address - No information available Public or Private Ownership – Private Proprietor - No information available Telephone Contact - No information available Type of Wheelchair Produced – Tricycles, Non-Foldables, Foldables How long has the workshop operated - No information available Currently operational - No information available Market are covered by this workshop - No information available 16. Name of Workshop - MADE

Nearest Town - Kampala District - Kampala Region - Central Postal Address - No information available Physical Address - No information available Public or Private Ownership – Private - NGO Proprietor – Disabled Women Entrepreneurs Telephone Contact - No information available Type of Wheelchair Produced – Foldables, Tri-cycles How long has the workshop operated - No information available Currently operational – Yes Market are covered by this workshop - No information available

17. Name of Workshop - Fort portal Orthopaedic Workshop, Buliga Nearest Town - Fort Portal District - Kabarole Region - Western Postal Address - No information available Physical Address - Mugulusi Road Public or Private Ownership - Private NGO Proprietor - KADIPU (Kabarole District Union) Telephone Contact - No information available Type of Wheelchair Produced - Hackstep How long has the workshop operated - No information available Currently operational – NO Market are covered by this workshop - No information available

- 18. Name of Workshop Kabenhas Metal Works Nearest Town - Kabale District - Kabale Region - Western Postal Address - No information available Physical Address - No information available Public or Private Ownership - Private Proprietor - No information available
  Telephone Contact - No information available
  Type of Wheelchair Produced - No information available
  How long has the workshop operated - No information available
  Currently operational - No information available
  Market are covered by this workshop - No information available
- 19. Name of Workshop Ocoko Vocational Rehabilitation Centre

Nearest Town - Arua District - Arua Region - Northern Postal Address - No information available Physical Address - No information available Public or Private Ownership - No information available Proprietor - No information available Telephone Contact - No information available Type of Wheelchair Produced - No information available How long has the workshop operated - No information available Currently operational - No information available Market are covered by this workshop - No information available

20. Name of Workshop – Masaka Vocational Rehabilitation Centre

Nearest Town - Masaka District - Masaka Region - Central Postal Address - No information available Physical Address - No information available Public or Private Ownership - No information available Proprietor - No information available Telephone Contact - No information available Type of Wheelchair Produced - No information available How long has the workshop operated - No information available Currently operational – Has never produced but only distributes Market are covered by this workshop - No information available

### 21. Other Workshops

Workshops making wheelchairs are also said to be in:

- Kamwokya in Kampala
- Benedictine Metal Workshop, Tororo
- Nebbi Town
- Muzira Workshop operated by Action for the Disabled
- Picaver in Jinja

### LIST OF MEMBERS IN THE STUDY TEAM

- 1. Mary Mukisa, Executive Director UNAPD Study Team Leader
- 2. Mabel Nawabira, Programme Officer UNAPD Team Member
- 3. Godfrey Mpagi, UNAPD Accountant Team Member
- 4. Okebe Onya, UNAPD Treasurer (Board Member) Team Member
- 5. Sempijja Mpiso, Co-opted Statistician Team Member