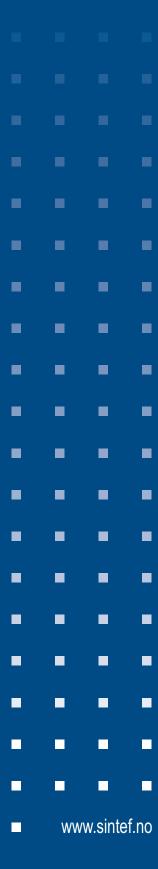
# **REPORT**



# Feasibility Study on Production and Provision of Wheelchairs and Tricycles in Uganda

Tone Øderud, SINTEF, Svein Brodtkorb, NAD, Ralf Hotchkiss, WWI

**SINTEF Health Reserach** April 2004







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TITLE

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CLIENT(S)

Whirlwind Wheelchair International Project (WWIP)

REPORT NO.	CLASSIFICATION	CLIENTS REF.		
A04 4509	Open	Einar Schultz, Arthur B. Schultz Foundation		
CLASS. THIS PAGE	ISBN	PROJECT NO.		NO. OF PAGES/APPENDICES
Open	82 614-03 498-1	78 45 10 35		36 / 1
ELECTRONIC FILE CODE				
Uganda Wheelchair Report		Tone Øderud One Odered	Sec. Sec.	
FILE CODE	DATE	APPROVED BY (NAME, POSITION, SIGN.)	A 11	
	2004-04-30	Arne H. Eide, Research Director	The T	. Dide

ABSTRACT

This study was commissioned by Whirlwind Wheelchair International Project in order to map the present situation pertaining to appliance technology, production and distribution in Uganda in general, and wheelchair technology, production and distribution in Uganda in particular.

The principal objectives of the study were to survey the needs for mobility devices; their present availability, quality and suitability and finally the present status of local production.

The team found that there is a lack of awareness, information and skills at many levels of the society in the field of disability and hence a need for training and capacity building of relevant stakeholders.

DPOs have a strong position in the civil society in Uganda and have been influential in legislation and policy processes in the country. In the field of legislation and policy development with relevance to persons with disabilities, Uganda can report substantial achievements. Although there is a long way to go before one can say that these achievements have had significant practical impact on the living conditions of persons with disabilities, they constitute a climate conducive for changes and improvements.

The team however concludes that there is a major *gap* between the need for mobility devises and the access to such devises in general and for children with disabilities in particular.

KEYWORDS	ENGLISH	NORWEGIAN	
GROUP 1	Disability	Funksjonshemmede	
GROUP 2	Wheelchair	Rullestol	
SELECTED BY AUTHOR Local Wheelchair Manufacturing		Lokal Rullestol Produksjon	

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#### 1. Executive Summary

This study was commissioned by WWIP in order to map the present situation pertaining to appliance technology, production and distribution in Uganda in general, and wheelchair technology, production and distribution in Uganda in particular.

The principal objectives of the study were to survey the needs for mobility devices; their present availability, quality and suitability and finally the present status of local production.

To achieve these objectives; the team studied information made available through meetings with relevant stakeholder in Uganda at all levels. The team studied available literature and documents. The team visited different production units in and around Kampala and in Tororo and Mbale towns. Finally the team attended a workshop organised by the Ministry of Health and NUDIPU, where the team had an opportunity to extract information and to discuss various aspects and challenges that the stakeholders face in their respective positions pertaining to production and distribution of appliances.

The team spent time at central level, visiting both wheelchair producers as well as providers. The team also went to Tororo District in order to observe the rural settings and the daily situation under which the majority of the people live; and the special challenges wheelchair users experience in a rural environment and the implications of living in the periphery.

#### Findings and recommendations

#### General

The team found that there is a lack of awareness, information and skills at many levels of the society in the field of disability and hence a need for training and capacity building of relevant stakeholders.

DPOs (Disabled Persons Organisations) have a strong position in the civil society in Uganda and have been influential in legislation and policy processes in the country.

In the field of legislation and policy development with relevance to persons with disabilities, Uganda can report substantial achievements. Although there a long way to go before one can say that these achievements have had significant practical impact on the living conditions of persons with disabilities, they constitute a climate conducive for changes and improvements.

In the search for data regarding "types of disabilities" and "needs for mobility devices" in Uganda; the team comprehend that there is a need for more complete statistics. The team however concludes that there is a major *gap* between the need for mobility devises and the access to such devises in general and for children with disabilities in particular.

#### Present types of mobility devices

In Tororo District the team had the opportunity to visit a number of wheelchair users in their home environment. The team came across basically three types of mobility devices; Huckstep wheel chairs, tricycles and imported hospital wheelchairs donated by charity organisations. The users reported that these had their advantages and disadvantages; the *Huckstep* is durable, it is good for domestic use and accessibility and gives more access to buildings in town. The *tricycle* is better for intermediate distance travelling and transport of goods and is preferred by traders and business people. None of these two mobility devices are suitable for long distance travelling where one is dependent on private or public transport. Neither the Huckstep nor the

tricyles are foldable and therefore basically denied access to public transport. The imported hospital chair is foldable, an advantage for transporting, but has its disadvantages in lack of durability and inappropriate technology. The chair easily breaks down in a rural environment and spare parts are not available.

#### Design

Most producers are concentrating on either the Huckstep model or the Tricycle because they are easily marketable due to the high demand. The *design* of Ugandan mobility devices needs to be upgraded in order to better meet the needs of various users groups and in order to meet the environmental demands. There is also a need to address the needs of children in particular, because most of the devices available to them are of adult sizes.

Availability of maintenance services and spare parts in rural areas is limited; basically because of present technology choice. The technology should build on bicycle technology enabling the users to draw on the bicycle services available in their locality.

#### Standardisation

To ensure proper quality and to avoid inferior domestic as well as imported wheelchairs flowing the market, standards and guidelines for import and production should be developed.

#### Cost – availability

The mobility devices are expensive and not easy for ordinary people to access. Lack of available funding for mobility devices is a major challenge and funding schemes as well as systems for provision should be established to ensure equity throughout the country.

#### Service delivery – distribution

The system for assessment, prescription and referral should be strengthened. This should include a clear definition of roles and responsibilities of various stakeholders

#### Production, assembly and maintenance of mobility devices

A system for production, assembly, distribution and maintenance of mobility devices needs to be developed. It needs to build on a decentralised system favouring supply and maintenance of mobility devices as near the consumer as practical possible. In order to secure highest possible quality in terms of durability and appearance and at the same time keep the cost low; the manufacturing could be divided between numbers of manufacturers, benefiting from respective comparative advantages.

#### 2. Acknowledgement

The team acknowledges, with a lot of appreciation all the positive support it received during the study in Uganda – in particular MOH for organising and NUDIPU for hosting a stakeholders workshop in November where the team was given an opportunity to meet and discuss with various aspects of appliance technology, production and distribution with professionals as well as users from various corners of the country.

We also would like to extend appreciation to the various stakeholders in Kampala area as well as in Jinja District and Tororo District for the frank, open and very useful response they gave to the team.

#### 3. Background

According to UN estimates, the population of people with disabilities (PWD) in the world is between 225 and 350 million people. This is based on a 10 % estimated prevalence rate [1], intended to cover severe, moderate and mild disabilities. The large majority of people with disabilities live in low-income countries<sup>1</sup>, very often living without optimal technical, medical or social support that could have improved their level of living conditions considerably. Disabled people are often marginalised and belong to the poorest segments of society. There is a clear link between poverty and disability, and the numbers of people with disabilities are continuously increasing due to wars, conflicts, accidents, the general aging population and the progress in health care ensuring the survival of more children who would have died of impairments.

Various baseline community surveys indicate a prevalence of 2-3% of PWDs in Uganda [2]. According to the 1991 Population and Housing Census, about 30 % of persons with disabilities had mobility difficulties, about 11,9% of persons with disabilities had visual difficulties and 13% reported to have hearing problems/deaf. A CBR survey carried out by Ministry of Gender, Labour and Social Development (MoGLSD) in six districts in 1996, indicated that 32,4% of people with disabilities had mobility difficulties, and only 2% of all the persons requiring mobility devices have this.

The Whirlwind Wheelchair Industrialisation Project (WWIP) is a joint venture between Whirlwind Wheelchair International (WWI) - USA, Atlas-Alliance - Norway, Arthur B. Schultz Foundation (ABSF)-USA and HandiNor A/S-Norway. ABSF and Atlas-Alliance have financed the initial stage of WWIP and are expected to implement the project in their respective programme countries. WWI has the technological expertise in wheelchair production in developing countries and HandiNor AS brings in the component of industrialisation to the project. WWI and HandiNor A/S have jointly developed a prototype wheelchair for the project.

It is the above four parties' belief that the bulk of current wheelchair distribution efforts in development countries neglect to address the fact that western wheelchairs are often unsuited for the conditions in these countries. WWI, who has been operating under the aegis of San Francisco State University, pursues a strategy where simple wheelchairs are produced and

<sup>&</sup>lt;sup>1</sup> Low income countries will be applied throughout this report to cover terms like developing countries, non-industrialised countries etc

distributed in the developing countries themselves. To date WWI has established 50 workshops in 40 different countries, with an estimated production rate of 5.000 wheelchairs per year. The strength of the WWI strategy is local production and distribution of a wheelchair appropriately tailored to the more demanding conditions in development countries. At the same time, this approach creates a higher degree of independence by creating workshops employing disabled wheelchair users. These workshops build wheelchairs, handle repairs and maintenance and thus help to create rare economic opportunities for local disability communities.

The drawbacks are that the production volumes are low compared to the need in the developing countries. It is also difficult for these workshops to benefit from new developments in material and production technology. Finally these workshops are small and their purchase capacity small, so they miss out on lower prices resulting from larger volumes.

The goals of the WWIP are to achieve high production volumes, and increased economic opportunity and independence in developing countries through long term industrialisation of the Whirlwind Wheelchair. In order to reach these goals, WWIP has undertaken modifications of the original WWI wheelchair and has developed a prototype that is believed to standardise a number of production processes and to maximise the use of local technology and materials.

Another goal of the WWIP is to achieve a sustainable wheelchair financing system, enabling the end users to get the wheelchairs at an affordable price.

#### Uganda

Uganda, which is one of the programme countries of the Atlas-Alliance, was selected because of the Alliance' long history in the country and the belief that it is one of the most appropriate countries in terms of local industry, local partners and structures, local competence and availability of materials.

Special thanks to NUDIPU, Ministry of Health, Ministry of Gender, Labour and Social Kampala School for the Physically Handicapped, Mulago Orthopaedic Workshop, MADE, Katalemwa Cheshire Home, Wheelchair Project – Jinja, RoadMaster Cycles (U) Ltd, COMBRA, TOOC – Tororo, Tororo District CBR Programme, Mbale Orthopaedic Workshop, Budaka Cheshire Rehabilitation Centre and all individuals contributing to the study with their highly valuable personal experiences.

#### 4. Objectives

The objectives of the feasibility study in Uganda are to make a survey of the

- needs for mobility devices like wheelchairs and tricycles
- availability, quality and suitability of wheelchairs and tricycles
- □ status for provision and local production of wheelchairs and tricycles

#### in order to

- □ strengthen existing manufacturers of wheelchairs tricycles
- assist the development of structured systems for provision of wheelchairs and tricycles
- assist PWD in accessing affordable wheelchairs.

#### 5. Approach/method

The feasibility study is based on information made available through meetings with relevant stakeholders in Uganda at the national and local level and available literature and documents. Two workshops were organized by Ministry of Health (MoH), the first in February 2003 hosted by NUDIPU and the second in March 2004.

#### 5.1 Meetings/Visits

Eight fruitful days including meetings and visits to stakeholders in Kampala, Jinja, Tororo and Mbale were organized by MoH (DPAR section) and NAD. Information and data were collected from organizations and private companies manufacturing wheelchairs/tricycles as well as bicycles, relevant ministries, DPOs, a school for physically disabled children, rehabilitation institutions, an institution providing training of field workers, PWD, etc.

List of stakeholders visited during the study:

- □ Ministry of Health Kampala
- □ Ministry of Gender, Labour and Social Development Kampala
- □ NUDIPU Kampala
- □ Kampala School for the Physically Handicapped Kampala
- □ Mulago Orthopaedic Workshop Kampala
- □ MADE Kampala
- □ Katalemwa Cheshire Home Kampala
- □ Wheelchair Project Jinja
- □ RoadMaster Cycles (U) Ltd Kampala
- □ COMBRA Seeta
- □ TOOC Tororo
- □ Tororo District CBR Programme Tororo
- □ Mbale Orthopaedic Workshop Mbale Hospital
- Budaka Cheshire Rehabilitation Centre

#### 5.2 Workshop on production and provision of wheelchairs.

Ministry of Health successfully organized a half day workshop hosted by NUDIPU. The most important issues discussed at the workshop were; production of wheelchairs, fitting of wheelchairs, distribution, maintenance & repair, standards and guidelines for quality assurance.

Twenty three persons participated in the workshop, representing MoH, MoGLSD, NUDIPU, USDC, MADE, Mulago Orthopedic Workshop, Katalemwa Cheshire Home, Mbale Othopaedic Workshop, various DPOs, NAD (Norway), Whirlwind Wheelchair International (USA) and SINTEF (Norway).





Photo: From the Workshop at NUDIPU

For detailed information see Minutes from the workshop and list of participants attached (Appendix).

#### 5.3 National Wheelchair Conference.

Ministry of Health successfully organized a National Wheelchair Conference from 3rd – 5th March 2004. The Conference followed up on the previous wheelchair workshop and the 3rd African Wheelchair congress held in Lusaka, Zambia August 2003. The types of wheelchairs needed, standards and guidelines for wheelchairs, production of wheelchairs, prescription, fitting, distribution, maintenance & repair were issues discussed.

More than fifty persons participated representing Uganda, Kenya, Tanzania, Norway and USA.





Photo: From the National Wheelchair Conference, March 2004, Tal Cottages

#### 5.4 Literature

Literature and documentation from Ministry of Health, Disability Prevention & Rehabilitation Section, Ministry of Gender, Labour and Social Development (CBR-programs) and COMBRA were made available.

#### 5.5 Definitions

The understanding of disability has gone through interesting developments in recent years. In some countries disabilities are still associated with "diseases" and stigmatised, but now the tendency is to focus more closely on the connection between the limitations experienced by individuals with disabilities, the design and structure of their environments and the attitude of the general population. Disability as a process involves a number of different elements at both the individual and societal levels. The understanding and application of disability will vary from one socio-cultural context to another [5].

The adoption of the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) [3] represents a milestone in the development of the disability concept. From 1980 and the first classification; the International Classification of Impairments, Disabilities and Handicaps (ICIDH) [4], a 20 year process has resulted in a shift in the WHO conceptual framework from a medical model (impairment based) to a new scheme that focuses on limitations in activities and social participation. The new ICF implies a much wider understanding of disability and the disablement process.

This functional and problem oriented approach based on activity limitations and social participation is important in order to understand the situation of many disabled persons, and to be able to change attitudes often reflected in the society towards people with disabilities.

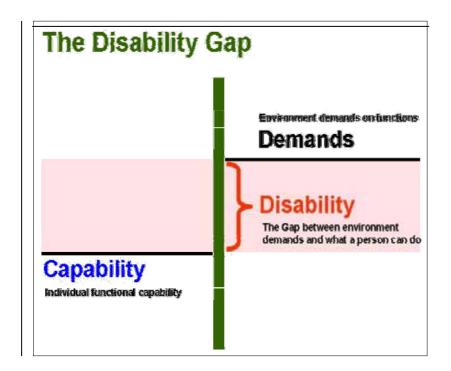


Figure: Disability Gap

Disability can be described as the gap between the environmental demands and the person's individual functional capacity. A disability can be reduced by making the environment more accessible or improving the persons capabilities. Assistive devices can be described as any device used in order to reduce the disability gap.

#### 6. Results/findings

#### 6.1 Awareness

There is reported to be lack of awareness, information and skills at many levels of the society. There is a need for proper training and capacity building of all stakeholders including

- people with disabilities and their families and friends
- □ local producers
- □ local communities including professionals, such as teachers, medical doctors, nurses and social workers
- □ field workers, occupational therapists, physiotherapists
- relevant ministries
- organizations of people with disabilities
- □ NGOs
- donor organizations

#### 6.2 Uganda Legislations and Government policies

#### National Policy on Disability

A national Policy on Disability was enacted in 2003 to guide the government sectors in development and implementation, in order to promote an enabling environment through empowerment, participation, human rights and inclusion of persons with disabilities in development processes.

#### **Universal Primary Education**

The UPE was introduced in Uganda in January 1997 as part of a government policy to provide free primary education to four children in every family, including orphaned and disabled children.

#### Uganda Constitution and Local Government Act

Persons with disabilities in Uganda are through the 1995 Uganda Constitution provided 5 seats in Parliament, one from each of the four regions and one representative for women with disability. Through the 1997 Local Government Act – persons with disabilities in Uganda are provided 2 seats in each and every of the local councils from LC 5 to LC 1, bringer the total number of PWDs represented in local councils in the country to more than 50000 individuals.

In the 1996 Children Statute, children with disability are provided with the right to appropriate treatment and rehabilitation and equal opportunities to education and social inclusion.

The 1999 Land Act provides persons with disabilities the right to tenure, ownership and management of land.

#### Decentralization

Through the passage of the Local Government Statute in 1993, the Uganda Constitution in 1995 and finally the Local Government Act in 1997, Uganda has dramatically changed the framework within which the local governments operate. Essentially the districts have now

more administrative, political and economic power, manifested in resources available, responsibilities and decision making autonomy than under the past centralised system. All departments, health, education, agriculture etc., operating at district level have become constituent units of the District Local Council (DLC) and operate under the supervision of the Chief Administrative Officer (CAO).

The greatest challenge to the decentralisation process is the ability for districts to sustain and run their own affairs, and attend to local needs and services. Local authority expenditure on the district health and social systems is to be improved by encouraging local authorities to take these as priority areas and to commit appropriate resources to them.

#### Government sectors

Ministry of Health (MoH), Ministry of Gender, Labour and Social Development (MoGLSD) and Ministry of Education (MoE) are actively involved in disability issues. This effort and commitment are of great importance in order to ensure equal rights for people with disabilities.

Within MoH there is a "Disability Prevention and Rehabilitation Section" that is now putting a lot of emphasis and focus on developing a "Policy on Production and Distribution of Assistive Devices". The policy aims at providing a direction for production and increasing accessibility of assistive devices to PWD within the socio economic setting. The establishment of a "Disability Council" will also assist PWD.

Department of "Disability and Elderly" is one out of six departments within MoGLSD. The department has special emphasis on CBR-programs focusing on inclusion of PWD in the society as a general principle.

Ministry of Education is involved in disabilities issues through "Special Needs Education". (SNE) is responsible for issues concerning children with disabilities attending school, and they have been purchasing some wheelchairs to schoolchildren with disabilities.

The legislations, strategies and activities being carried out in the ministries, at governmental level and at district level, are of major importance for building awareness of disability issues and supporting people with disabilities. During the visit it was identified a need for standards and guidelines for wheelchairs and tricycles approved by the national authorities.

#### 6.3 Disabled Peoples Organisations (DPO)

Uganda has various organizations for people with disabilities working towards empowerment of people with disabilities and increases their opportunities to participate in society. NUDIPU (National Union of Disabled Persons of Uganda) is an umbrella organisation that brings together people with all types of disabilities including physical, sensory and cognitive disabilities.

There is now a very strong disability movement in Uganda. NUDIPU and the disabled people's organisations have successfully influenced the legislation and Governmental Strategies in favour of PWD. Awareness about assistive devices has been raised through different ministries, DPOs and CBR programs. Despite this effort there is still a huge need for awareness and capacity building.

#### 6.4 Type of disability

There have been difficulties in obtaining statistics on different types of disabilities. According to the 1991 Population and Housing Census, about 30 % of persons with disabilities had mobility difficulties, almost 12% of persons with disabilities had visual difficulties and 13% reported to have hearing problems/deafness. A CBR survey carried out by Ministry of Gender, Labour and Social Development (MoGLSD) in six districts in 1996, indicated that 32,4% of people with disabilities had mobility difficulties. Polio, Cerebral palsy, injuries and accidents are reported to be major causes of current disabilities. A need has been identified a need for more complete statistics on disability issues.

#### 6.5 Need for mobility devices in Uganda

According to the Population and Housing Census (1991) and the CBR survey carried out by Ministry of Gender, Labour and Social Development (MoGLSD) in six districts (1996), approximately 30-32 % of persons with disabilities have mobility difficulties and only 2% of the persons requiring mobility devices have them. The figure indicates that there is a major gap between the need for mobility devices and the access to such devices. Relevant data for the exact need of wheelchairs and tricycles has not been available for this study.

It is reported to be difficult for PWD, especially out in the villages, to get access to wheelchairs and tricycles. Tricycles are more frequently asked for then wheelchairs out in the rural areas. Tricycles might be used for longer distances than wheelchairs, but are not suited for indoor use. Tricycles are usually more appropriate for people with lower levels of disability, such as those also using crutches, than for wheelchair users having a higher level of disability.

Many PWD use their tricycle for carrying goods as part of their own businesses. Lack of access to assistive devices hinders PWDs from starting a professional careers, earning their living and contributing to society. It causes great limitations for PWD when entering into the job market.

Transport is a major problem for many wheelchair riders. It is reported that some buses are refusing to take on the wheelchair or you have to pay two or three times the ordinary ticket price for bringing the wheelchair. It is also reported that the wheelchairs are often damaged from falling off the vehicle during transport.

Many children are using mobility devices that are designed for adults, and then there is a risk of harming the child. There is a lack of wheelchair models designed to fit the needs of children especially children with severe disabilities. Suitable mobility devices might enable the children to attend school and actively take part in the society. One of the informant's comments was: "The Huckstep wheelchair is a nightmare for CP-children" which indicates the need for developing new wheelchairs designed to fit children.

As a conclusion there is a huge gap between the need for mobility devices and the access to such devices. The registered needs for mobility devices in Uganda are currently not met. The wheelchairs need to be functional, durable and fitted to the local environment. Spare parts and repair need to be locally available. The wheelchairs have to be designed in order to be easy carried on public and private transport.

#### 6.6 Visiting wheelchair users in the field registered by the CBR Programme

#### 6.6.1 Purpose of the visit

Since the team, while in Kampala, focused on meeting stakeholders and studying wheelchair production units, a visit to the rural Tororo District was made to focus on wheelchair users/potential users and on environmental aspects affecting wheelchair use.

General objectives of the study in Tororo District

The objective of the study was to investigate following aspects:

- (i) environmental conditions in terms of mobility and accessibility in the field
- (ii) the role of wheelchairs and tricycles as means of transport
- (iii) local technology in production and maintenance of wheelchairs and tricycles

#### **6.6.2 CBR Programme in Tororo District**

The Community Based Rehabilitation Programme in Tororo District is coordinated by the District Rehabilitation Office. It is a multi sector programme where departments of Rehabilitation, Education, Health, Agriculture and Community Development etc. are the main government stakeholders, and the Disabled persons organisations (DPO) and other service provision organisations are the main civil society stakeholders. The programme has a cross disability approach and targets all kinds of disabilities.

On the one hand the programme aims at building the capacity of the civil servants within the respective sectors in the local government structures, from district to village level; including administration staff and technical staff, teachers, social workers, health workers and field extension workers etc.

And on the other hand it aims at improving the lives of persons with disabilities through various types of intervention in the community:

The former is done through general interventions including:

- □ build awareness of disability and change attitudes
- promote more equitable opportunities and access to general systems of society, and general interventions in the environment
- increase the representation of persons with disabilities on formal and informal bodies with authority to decides plans, services etc. for persons with disabilities
- promote and protect disabled peoples human rights

The latter is done through more specific interventions including:

- □ functional training in self-care, mobility, behaviour and communication
- referral to appropriate health services and provision of appliances and technical equipment to facilitate training to alleviate consequences of disability
- accessibility measures in home and community
- sensitisation and information to create more positive attitudes among pwd, parents and the community at large
- □ inclusive education in mainstream schools
- □ formal and informal vocational training
- □ income generation

The CBR programme is active in all the Sub-Counties of Tororo District.

#### 6.6.3 Interviewing wheelchair users in the Tororo District

#### Abuna Osilo – (55) – Ropemaker

Abuna uses a Huckstep Wheelchair which he got from the CBR programme, free of charge, 7 years ago. Its canvas seat back and footplate was missing, but had been replaced with some pieces of wood. Apart from that, the chair had been very durable. Tyres and tubes had been replaced approximately every other year. He is satisfied with the wheel chair's ability to take him around in the compound, but he needs assistance to climb the small mound to reach the main road, 1 metre above the level of his compound. His wheels have a tendency of lose the traction and spin. Going down the same slope /mound is also difficult because the chiar tends to tip forward..

He never brings the wheelchair when visiting Tororo town.

He basically relies on bicycle repair and supply facilities in or around Tororo town.

His main income was rope production. He also earned some extra money doing millet weeding for neighbours. His overall income was approximately Ush 30.000,- a month , mainly from the ropes.



Photo: Visiting Mr. Abuna Osilo, Ropemaker

#### Ms. Immaculate Abbo (25) – fish trader

Ms. Immaculate got a Huckstep wheelchair in 1994, but it broke down in 1997. Her main problem was the tyres and tubes that got spoiled too frequently. The chair was now dismantled, and it had been stored under a tree at the compound since 1997. But all parts, apart from bolts and nuts, were still there.

She had also received a tricycle from Tororo Ophthalmic/Optic Centre in 1997. The tricycle is the basis for her trading business. She goes to the trading centre 5 kilometres away once a week to collect fish which she sells in the market nearby. This gives her a profit of approximately Ush 2000,- per trip. In addition she undertakes transport of water for the family.

She has never used the tricycle for long distances; for example going to Tororo town.





Photo: Ms. Immaculate Abbo (25) riding her tricycle and testing the new wheelchair from WWI

#### John Omollo (11)

John Omollo was born without a disability, but he had a strong attack of malaria at the age of 9 months and developed CP. At that time he started to roll back and forth on the ground, but with assistance from the CBR Programme in Tororo, he is now able to sit up right. The CBR workers hope with continued effort that he one day will be able to move in a wheel chair or eventually be able to walk shorter distances. At present the father takes him around within the compound in a frail stroller for children. John Omollo was given a ride in Ralf's wheelchair and laughed joyfully.



Photo: John Omollo riding Ralf's new wheelchair from WWI (prototyp)

#### Monday Oriemakin (60) - District Councillor (PWD)

Monday stays with his wife and his children west of Tororo town. He was elected councillor in his sub-county 8 years ago, and at present he has the position as Chairman of the Finance Committee in his sub-county.

Monday has a standard Huckstep wheelchair, which he got from Mulago Hospital more than 10 years ago. He has maintained it well. He repaints it and buys new tyres and tubes every two years. He basically relies on bicycle repair and supply facilities in Tororo town.

He moves frequently to Local Council Meetings 5 kilometres away from home with hired assistance.

He has about 2-3 acres on which he grows millet, maize, sorghum, potatoes and banana. He has also planted Moringa trees as cash crop, which gives him substantial income.

He finds the Huckstep useful within his sub-county, but when travelling outside, either to Tororo town or to Kampala, it is expensive and complicated to bring the chair on public transport. They normally charge him three times ordinary ticket price when he brings the wheelchair with him. As a consequence, he has stopped bringing the chair with him, and now relies on peoples support at the other end. NB! Last time he was on public transport to and from Kampala, the wheelchair fell off the vehicle on the highway; an incident that has contributed to the decision to leave the chair behind when travelling.



Photo:District Councillor Mr. Monday Oriemakin and his wife

## 6.6.4 Reflections regarding environment and accessibility after visiting the homes in the villages:

Although Tororo District and parts of Mbale District are flat, the condition of footpaths and tracks in the villages is a constraint upon the use of wheelchairs and tricycles. Improvement of

these tracks could expand the ability of persons with disabilities travel independently with their wheelchairs and tricycles. The needs of the persons with disabilities for improved tracks in and around the villages coincide with the needs of persons dependent on bicycles, either as means of commercial transport of people or transport of produce to the market. The CBR programme should therefore not meet a lot of resistance when addressing this issue and introducing the idea of improving these tracks to the community.

In a study undertaken in Eastern Uganda on intermediate means of transport "Bicycles and Rural Women in Uganda" (World Bank-1994), 4 alternative types of low-cost vehicles were identified as most appropriate to the local conditions: bicycles, wheelbarrows, oxen/cows and donkeys. The study looked into possible ways of reducing the burden on women in terms of collecting water, firewood, going to grinding mills, and also into possible ways of improving income generation.

On one hand persons with disabilities should be able to compete in this niche of the transport market with their tricycles, and on the other hand with some innovation they could expand alternative means of mobility into areas were wheelchairs and tricycles cannot now go..

#### 6.6.5 Kapchorwa District

The team made a brief visit to Kapchorwa Trading Centre at the slope of Mount Elgon (Masaba) on Sunday afternoon. The area is extremely inaccessible in terms of wheelchair usage and alternative mobility measures needs to be studied. Donkeys are not traditionally kept in districts like Tororo and Mbale, but are much more common in Kapchorwa. At the time of the visit, a number of donkeys were spotted. Donkeys in this area are basically used for the transport of agricultural produce.

Since very few mobility options are available in steep and mountainous areas like Kapchorwa District, some innovations are needed to meet the mobility needs of persons with disabilities. One avenue that could be given more attention is the utilization of donkeys; either directly or in combination with carts. Another option is the development of more stable wheeled chairs, with lower gearing, that could travel on the steeper slopes of many village pathways.

#### 6.7 Status for local production of wheelchairs and tricycles

Uganda has few production points for assistive devices which are unevenly distributed [2]. Orthopaedic Services and manufacturing of wheelchairs where initially started in 1967 by Dr. Huckstep within the Mulago Orthopaedic Workshop. Currently Uganda has few production sites and workshops manufacturing, adapting and repairing wheelchairs and tricycles. The majority of the existing workshops are small and un-evenly distributed throughout the country. Production capacities in existing workshops focusing on assistive devices are relatively low. The majority of the workshops are manufacturing the three wheel Huckstep model which is a non-foldable wheelchair. MADE is manufacturing the foldable four-wheeler Whirlwind Wheelchair model Africa 1. Huckstep is reported to be very durable and robust, but it is usually difficult and often impossible for a person using the Huckstep to enter private homes and public buildings. Transfer from the Huckstep wheelchair to bed or another chair is also reported to be very difficult for many potential users. It is also difficult to bring the Huckstep wheelchair on public transport like buses and cars. The Whirlwind wheelchair can more easily be used inside houses, and it is easier to bring the Whirlwind wheelchair on public and private transport because it is foldable. Both the Huckstep and the Whirlwind are using locally available parts for repair and maintenance.

Some workshops like Katalemwa are focusing on devices for children, but there is still a need for more knowledge about the design and adaptation of suitable mobility devices for children throughout Uganda.

Many of the wheelchair workshops (MADE, Katalemwa Cheshire Home, Mulago Orthopaedic Workshop, Wheelchair Project – Jinja, Tororo Ophthalmic/Optic Centre, Mbale Orthopaedic workshop and Budaka Cheshire Rehabilitation Centre) have skilled staff being trained as wheelchair technologists, orthopaedic technicians or occupational therapists.

#### Mulago Orthopaedic Workshop, Kampala

Mulago Orthopaedic Workshop is a governmental workshop seated at the premises of Mulago Hospital in Kampala. Mulago is making orthopaedic appliances and is the National referral hospital for all orthopaedic issues.

Orthopaedic Services and manufacturing of wheelchairs where initially started in 1967 at Mulago Orthopaedic Workshop by Dr. Huckstep. Up to now the workshop has been manufacturing the Huckstep wheelchair. Manufacturing of wheelchairs has for many years been the monopoly of Mulago, but now there is a lack of funding. Mulago Orthopaedic Workshop used to produce 200 chairs per month but now the production has been reduced greatly.



Photo: Huckstep Wheelchair being produced at Mulago Orthopaedic Workshop, Kampala





Photo: From Mulago Orthopaedic Workshop, Kampala

#### MADE, Kampala

Mobility Appliances by Disabled Woman Entrepreneurs (MADE) is a non-profit making organisation, set up with the main objective of providing means of mobility to persons with disability. MADE was formed as a response to the need for suitable and good wheelchairs in Uganda. MADE is currently manufacturing the standard Whirlwind foldable four-wheeler known as the Africa 1. The wheelchairs are made of locally available materials and components, which can be serviced and repaired locally.

MADE is the first organisation run by women with disabilities to venture into this male dominated sector. MADE has enabled more than 500 people with disabilities to gain mobility with either crutches or wheelchairs.



Photo: Ms. Fatume Acan and Ms. Sharifa Mirembre at Made

The current capacity of MADE is the manufacture of about 15 wheelchairs each month, and currently MADE are also making tricycles.



Photo: Technicians, Sharifa and Ralf working at Made, Kampala





#### Katalemwa Orthopaedic Workshop, Kampala

Katalemwa Orthopaedic Workshop is based in the Katalemwa Cheshire Home and Rehabilitation Centre, eight kilometres north of the capital Kampala. Katalemwa Chesire Home was founded in 1970. Initially the home was set up to provide a family home environment for children with physical disabilities. In 1992 the emphasis changed from long-term residential care to short term rehabilitation. The home is working with Community Based Rehabilitation workers. Katalemwa Cheshire Home organises regular training sessions for physiotherapists, orthopaedic technicians and physiotherapy assistants from other projects in Uganda. There are 54 beds, with most residents under 20 years old.

Katalemwa Orthopaedic Workshop is manufacturing various orthopaedic appliances, wooden seats for disabled children, wheelchairs and tricycles. Workshop staff includes four Orthopaedic Technicians.

By the start of 2003, the workshop had produced 110 wheelchairs and 20 tricycles for disabled children. This service has provided children in the home with the ability to get out and about. It also enables them to leave the residential service, after a period of physical rehabilitation, and return home to live with their families and go to school using their new wheelchair.

The workshop produces a foldable small-sized child's wheelchair and a medium-sized junior model using ordinary and locally available bicycle parts and materials, based on the Whirlwind Wheelchair International design. The workshop operates in premises built with funds from Leonard Cheshire International. CBM, Rotary clubs and individual donors fund the running of the workshop and materials for the wheelchairs.

The price for a foldable wheelchair is about Ush 250 000,- and for a non-foldable wheelchair Ush 200 000,-. The price for a tricycle is about Ush 300 000,-.





Photo: Tricycle and children wheelchairs being produced at Katalemwa Orthopaedic Workshop

#### Wheelchair Project – Jinja

Wheelchair Project – Jinja started in 1986. Staff includes one leader and two technicians. The workshop is focusing on manufacturing of tricycles. The users are often utilising the tricycles for professional purposes generating their income. The Wheelchair Project has tools and jigs for manufacturing of tricycles. The project is currently manufacturing the Huckstep wheelchair. The capacity is about 40 tricycles or 20 wheelchairs each month.

The price for the wheelchair is about Ush 180 000,- and for a tricycle Ush 230 000,-



Photo: From Wheelchair Project Jinja

#### Private workshop in Kampala

There are some private workshops emerging to fill the demand for assistive devices in commercial centers with close links to Mulago Orthopaedic Workshop in Kampala. These workshops were not visited during the limited feasibility study. There are also some smaller workshops out in the districts that were not visited also due to limited resources and time.

#### RoadMaster Cycles (U) Ltd

RoadMaster Cycles, being a commercial manufacturer of bicycles in Kampala with about 100 shop employees, has huge capacity, but they lack basic knowledge about the use of wheelchairs and the needs of wheelchair riders. They are purely an industrial manufacturing plant, currently offering manufacturing of wheelchairs on request. RoadMaster is able to effectively manufacture parts and products according to given specifications.

Our main concern is that RoadMaster does not have sufficient knowledge about user needs and about the design of a functional wheelchair. In 2002 RoadMaster received an order from DANIDA, and they manufactured a very wide Huckstep wheelchair that did not facilitate easy accessibility for PWD. RoadMaster was also indicating that they would like to go into manufacturing of the old "hospital type" wheelchairs which is not made for the outdoor environment of Uganda. These chairs will not enable PWD to live independently.



Photo: Tricycle from RoadMaster





Photo: Manufacturing of bicycles at RoadMaster

#### The Community Based Rehabilitation Alliance (COMBRA),

COMBRA is a training centre undertaking training of both professional health care workers and people with disabilities. COMBRA is running a 16 week course for field workers, and they are also offering shorter training courses. Since 1994 about 260 persons have attended seminars at COMBRA.

COMBRA has a small workshop manufacturing simple devices like sticks, canes, toys for children with disabilities, toilet seats, etc. COMBRA is not manufacturing wheelchairs or tricycles.





Photo: Devices made at COMBRA workshop

#### Kampala School for the Physically Handicapped

Kampala School for the Physically Handicapped is a well organised school and vocational training centre for children and youths with disabilities. Cerebral Palsy was reported to be the major disability. The school is training the students in theoretical skills and practical skills. The staff also focuses on improving the attitudes towards people with disabilities, including the attitudes of the parents.

Kampala School for the Physically Handicapped does not manufacture wheelchairs or tricycles, but they have received some donated wheelchairs from The Wheelchair Foundation.





Photo: From Kampala School for the Physically Handicapped – Visiting the classroom





Photo: From Kampala School for the Physically Handicapped -Vocational Training

#### Tororo Ophthalmic/Optic Centre

The team visited the Tororo Ophthalmic/Optic Centre that basically includes an eye clinic and assistive devices workshop. The centre runs eye services with a consultant seconded from Ministry of health. They have a CBR program in Tororo and Bunyore counties using 20 community resource persons who are paid to carry out CBR activities in the community. The technical staff from different government departments facilitates CBR activities through outreach services. Furthermore, the center has recruited an Occupational therapist and is in the process of getting a second one.

They produce both wheelchairs (Huckstep) and tricycles (a modified and improved version of the one that is produced at Cheshire Homes in Kampala). They concentrate at present on tricycles and the production capacity is approx 60 tricycles a month. The type they are producing is durable and user friendly (Ralf Hotchkiss found it one of the most comfortable he ever has tried!). This tricycle uses 28" tyres both rear and in front. Most available dimension in the market is 28", second is 26", while 24" will have to be purchased from Kampala. The price of a complete 28" wheel is Ush 17.000,-

(USD 8,5), while the 26" is 50 % more than that. A 24" wheel from Kampala will most likely be the double of the 28", exclusive of the transport cost.





Photo: Visiting Tororo



Photo: Ralf meeting a young Wheelchair rider from Tororo

#### Mbale Orthopaedic workshop at Mbale Hospital

The team visited Mbale Orthopaedic workshop, which used to be a satellite workshop to Mulago Hospital in Kampala.

The workshop produces all types of orthopaedic appliances and serves 18 districts in the eastern part of the country. Wheel chair production has been going on only for the three last years. They produce the standard type Huckstep.

Since decentralization the hospital has struggled financially, because the financial allocation from the district is insufficient. The system of cost sharing with clients that was established to enable the hospital meet its costs, and for the orthopedic workshops to keep up the production volume, was abandoned in 2001. This put the entire cost of the production on the hospital itself, and has resulted in a downward trend in production of appliances. From 2001 to 2003 the number of clients served fell from 900 individuals to 300 individuals in Mbale Orthopedic Workshop.

The Mbale Orthopedic Workshop has been instructed from Presidents Office not to produce tricycles. The reason:

According to Ugandan law, persons with disabilities are exempt from custom taxes. Along the border between Uganda and Kenya (near Tororo and Mbale) some persons with disabilities have gone into joint ventures with local businessmen, smuggling goods on their tricycles from Kenya into Uganda. As a measure against this the Government has put restrictions on tricycle production in the area!!?

Some of the conclusions from the meeting in Mbale Hospital were:

- □ There is a need for lobbying the district politicians to secure more funds for the health facilities in the district.
- □ In addition there is a need for establishing a disability fund at district level for paying appliances.

MOH is planning to strengthen "private for profit workshops". The Government plans to abandon their own production of appliances and leave it to private for profit workshops. The role of the government will basically be to develop policies and guidelines for production and quality assurance. The government will in turn buy appliances from these private producers. As for development of policies and guidelines for appliance production; MOH – Disability Prevention and Rehabilitation Section has already started this work.



Photo: Visiting Mbale Orthopedic Workshop

#### Budaka Cheshire Rehabilitation Centre

Not supported by Cheshire Homes –UK. Gets some support from the Diocese of Tororo.

A rehabilitation center with a ward for 20 persons. They see about 100 people with disabilities a year, mainly polio and osteomyelitis, keeping people for up to three months, for short term rehabilitation.

Staff includes an orthopedic surgeon and physiotherapists. They do not have their own appliance and wheelchair production at the center.

They used to get wheelchairs from Cheshire Homes in Kampala, but the price is approximately Ush 200.000,- per unit, and therefore not affordable to the center. They got 40 Chinese wheelchairs last year – prescribed by Mbale Hospital. It was a gift from Rotary - Uganda. 9 out of these 40 wheelchairs are reported to have broken down within less than a year, but the number is most likely even higher due to underreporting.





Photo: Wheelchair riders and tricycles riders from Budaka Cheshire Rehabilitation Centre

#### Other Workshops

Disabled peoples organizations have also opened workshops in Kabale, Lira and Gulu.

Name/place of workshop	Type of wheelchair and tricycle	Capacity (full production)
Mulago Orthopaedic	Huckstep – non foldable	Wheelchairs – 30 - 60 pr.
Workshop, Kampala		month
		Max: 200 pr. month.
Katelemwa Cheshire Home,	Huckstep – non foldable	Wheelchairs – 150 pr. year
Kampala	Whirlwind - foldable	Tricycles – Just starting
	Focusing on children	
	Tricycles	
MADE, Kampala	Whirlwind /African 1 –	Wheelchairs – 15 pr. month
	foldable	Total production of 75
	Children's wheelchairs	wheelchairs for 2003
	Tricycles	
Wheelchair project - Jinja	Huckstep – non foldable	Wheelchairs – 20 pr. month
	Tricycles	or
		Tricycles – 40 pr. month
Tororo Ophthalmic/ Optic	Huckstep – non foldable	Wheelchairs –
Centre, Tororo	Tricycles	Tricycles - 60 pr. month
Mbale Orthopaedic	Huckstep – non foldable	
Workshop, Mbale		
Budaka Chesire Home,	Have received donations	No manufacturing of
Tororo	from Rotary Uganda.	wheelchairs and tricycle.
D Dr. W 1	TT 1 ( C1111	W7 11 : 1500 : 2002
RoadMaster, Kampala	Huckstep – non foldable	Wheelchairs - 1500 in 2003
	Children and adults	Tricycles – Up to now a few
	(unnecessarily and	samples, but capacity could
	extremely wide chairs)	be high

Table 1: List of workshops visited, type of wheelchairs and estimated full capacity from the information being made available.

The prices for the wheelchairs varies from Ush 160 000 - 275 000,-The tricycles cost slightly more, around Ush 270 000 - 300.000,-

Many of the workshops have not calculated their total costs for manufacturing and distribution of wheelchairs and tricycles. There is a need to calculate the actual costs for manufacturing of wheelchairs, in order to estimate a proper sales-price as well as to form a **more effective** basis for cost cutting.

#### 6.8 Funding of the workshops

The orthopaedic workshops (except the commercial workshops) have three sources of funding; donors, governmental and internal generated funds.

Mulago Orthopedic Workshop has since 1999 been dependent on governmental support. The hospital is paying employees' salaries and the costs of materials are supplied by the Ministry. It is reported that there has been lack of funding that has led to lack of available wheelchairs.

MADE and Katalemwa Cheshire Home have received some funding from donors and from internal funds. The funding has to cover material costs, equipment, fixed costs and utilities (renting of buildings, electricity, water, cleaning, etc) and salaries.

#### 6.9 Funding of assistive devices

Funding of assistive devices is a major challenge. Many people with disabilities are not able to pay the costs for their appliances. There are some institutions and NGOs that provide funding for assistive devices, but the huge need for mobility devices is currently not met. Lack of funding for wheelchairs and tricycles is one of the major challenges that is limiting the active participation and contribution of people with mobility difficulties to the development of Ugandan society.

#### 6.10 Donations

There are international- and national organizations (Wheelchair Foundation/Rotary) donating wheelchairs to selected institutions/ organizations and individuals. The majority of these wheelchairs are similar to the very old fashion "hospital wheelchairs" which are <u>not</u> suited for the rough environment of Uganda. Donated wheelchairs are often distributed to individual persons without proper assessment and follow up. It is reported that 250 wheelchairs are distributed in one day and it is impossible to do proper assessment, prescription, individual adaptations and follow up in such a short time.

Other major problems are that there are no spare parts available and no mechanism for quality control of donated wheelchairs. Many of the donated wheelchairs are of poor quality and many of the donated wheelchairs are reported to have broken down within less than one year. With no spare parts available it is almost impossible to have the wheelchair serviced and repaired.

The donated wheelchairs are donated free of charge to the user. The system of free appliances is not sustainable within the existing systems in Uganda. Reselling of wheelchairs is a problem. It is reported that some people receiving free donations are selling their wheelchair to the highest possible price. This is undermining the existing systems and has to be addressed in order to achieve a sustainable system benefiting all people with disabilities regardless of economical status.



Photo: Donated wheelchair from Wheelchair Foundation.

#### 6.11 Standards

There is identified a huge need for technical and functional quality improvement of existing wheelchairs in Uganda. Today there are no common standards or test methods in order to ensure a minimum quality of wheelchairs, tricycles and other assistive devices. It is a huge need for both technical and functional standards and guidelines for wheelchairs and tricycles in Uganda.

There exists both international accepted standards and standard designed to meet the need in development countries. This information can be made available for Uganda in order to develop standards specially suited for the country and benefiting people with disabilities.

Donated wheelchairs and locally made wheelchairs need to comply with the minimum standards accepted for Uganda. When such standards are in place and accepted by the Ministries all wheelchairs being used in Uganda have to comply with this standards and this will avoid low quality donated wheelchairs to be distributed in Uganda. The development of appropriate standards and test procedures will also challenge the local manufacturers to develop and produce better quality wheelchairs benefiting people with disabilities in Uganda.





Photo: Damaged front caster and testing of materials. It is a huge need for guidelines and standards on materials, components, finished products and test methods

#### 6.12 Existing structures for provision of wheelchairs and tricycles

Service providers and end-users (PWD and their families) face multifaceted challenges in providing and accessing assistive devices [2]. One of the problems reported is that it is difficult to reach PWD out in the rural areas, make them aware of the wheelchair services and assess their needs. Even if they are made aware they have great difficulties in getting access to such services due to poverty/lack of funding and the long distance they have to travel in order to get a wheelchair.

There is no clear policy on production and distribution of assistive devices, but the MoH is currently working on such a policy. This policy will be an important document, facilitating the availability of assistive devices in Uganda.

#### 6.13 Follow ups

There is reported to be no structured system for follow up of the users. It is crucial to follow up the user and find out how the devices are being used by the user in her/his daily life. The devices have to be adjusted to fit the users need and the environmental demands. The devices also need to be serviced and maintained. Proper follow up is almost none existing. The lack of follow up is a huge challenge out in the local communities and even in the more urban areas.



Photo: Photo illustrates the importance of follow up in order to avoid misuse of devices which can harm the person.

#### 6.14 Service and repair of wheelchairs & tricycles

There is yet no well-established system for repair of assistive devices including wheelchairs and tricycles in Uganda. Many PWD out in the villages do not have any access to repair, and those who have are usually approaching local bicycle shops and artisans for handling the repair.

A severe lack of skills is reported among local stakeholders and community artisans for proper repair of assistive devices although CBR programmes endeavour to provide low cost appropriate aids in the communities.

#### 7. Concluding Remarks and Recommendations

#### 7.1 Concluding Remarks

There is a very strong disability movement in Uganda. NUDIPU and other organisations for people with disability have successfully influenced the legislation and Governmental Strategies in favour of PWD. The development of policy, legislation, strategies and activities being carried out at governmental level and at district level are of major importance for creating awareness about disability issues and supporting people with disabilities. Uganda is a pioneer country in Africa providing five seats in Parliament for people with disabilities and two seats for people with disabilities in each and every of the local councils. Awareness of technology that is appropriate for people with disabilities has been raised through the disability movement, different ministries and CBR programs.

Despite this effort there is still a huge need for awareness and capacity building. There is a major gap between the need for mobility devices and the access to such devices. The conclusion is that the registered needs for assistive devices in Uganda are currently not met and there is a need for capacity building and raising awareness about disability issues and assistive devices. The design of Ugandan wheelchairs needs to be upgraded in order to better meet the needs of various user groups and in order to meet the environmental demands. There is also a need for wheelchairs specifically designed to fit children.



Photo: Old Huckstep Wheelchair

#### 7.2 Recommendations

The following recommendations are brought forward (not in order of priority):

#### Standardisation

Establish and approve national standards and test methods for wheelchairs in Uganda. It is highly recommended to establish a working group in order to work out minimum standards (technical and functional) for wheelchairs. The working group should include all relevant stakeholders like: professionals (occupational therapists/physiotherapists, orthopaedic officer, district rehabilitation officer), manufacturers of wheelchairs, wheelchair users, etc. Furthermore establish a National Committee that has the authority to control and make sure

that every wheelchair on the Ugandan market has to comply with the accepted standards. All wheelchair manufacturers, suppliers, non-governmental institutions donating wheelchairs, etc have to make sure that their wheelchairs do comply with the approved standards.

#### Wheelchairs for children

Establish and fund development project for developing new wheelchair designs for children, including special seating. Children are not small adults and there is a lack of wheelchair models designed to fit the needs of children especially children with severe disabilities. Suitable mobility devices might enable more children to attend school and actively take part in the society.

The developments of new children's wheelchairs and special seating have to be followed by training of the manufacturers, the field workers, the local health care worker and the parents. Knowledge about adapting wheelchairs to fit each individual child is highly needed. Special attention should be made to children with sever disabilities (Cerebral Palsy, Muscular Dystrophy, etc.).

#### Available spare parts

Enhance local availability of spare parts and make sure that maintenance and repair can be done locally. Include requirements for availability of and access to spare parts in the new national standards. Any organisation (governmental or non-governmental) should not be allowed to procure wheelchairs without including a guarantee on availability of spare parts.

#### Maintenance, service and repair of wheelchairs and tricycles

Basic service and repair of wheelchairs and tricycles have to be made available throughout the country. Local workshops and artisans should be trained to do basic repair and maintenance.

The user and his/her family have to be made aware about the importance of maintenance, cleaning and simple repair of the wheelchair and they need basic skills about these important issues.

#### Awareness and advocacy

Knowledge and awareness about disability issues and provision of assistive devices like wheelchairs, tricycles, crutches, etc. should be brought forward to all stakeholders including people with disabilities and their families and friends, local producers, local communities, teachers, medical doctors, nurses, social workers, field workers, occupational therapists, physiotherapists, relevant ministries, organizations of people with disabilities and donor organizations.

#### Training of field workers and local health care workers

Knowledge and awareness about disability issues and assistive devices should be included in existing CBR-programs and in the curriculum for training of field workers and front line health workers.

#### Structures for service delivery of assistive devices (Assessment, prescription and referral)

The system for assessment, prescription and referral should be addressed. The roles and responsibilities of the stakeholders in the service delivery process need to be defined. One of the key challenges is that the professionals being authorised to do the prescription are located in the urban areas, and people out in the local communities do not have access to such services. Establish local and national structures for developing structured systems for service delivery is needed. The first initial step could be incorporated in ongoing CBR-programs and in ongoing activities and policies organized by relevant ministries and organizations of people with disabilities.

A service delivery system for provision of assistive devices (wheelchairs) includes:

- □ identifying users in their local community
- □ assessing user needs
- prescription of assistive devices
- □ identifying proper assistive devices
- □ individual fitting of assistive devices
- □ training of the users and the users family
- □ follow-up of the user in his/her local environment
- repair and services

#### Funding of assistive devices

Establish disability funds/funding schemes and systems for provision of assistive devices that ensure equity throughout the country. Disability funds should be established at both national and district level in order to enable the users to acquire proper assistive devices in any local district. Lack of available funding for assistive devices is a major challenge.

#### Strengthen local manufacturers

It is crucial to strengthen existing local manufacturers of wheelchairs and tricycles. This is needed in order to enable the manufacturers to ensure proper quality and the possibilities of providing individual fitting/ adaptation of the devices. The wheelchairs have to comply with the standards, meet the individual needs and meet the environmental demands. The prices must be affordable.

Implementing national standards, training of local manufacturers and collaboration between governmental organisations, non-governmental organisations and manufacturers might strengthen the manufacturers. The manufacturers have to provide high quality wheelchairs and tricycles that are functional, durable, robust, easy to adapt to the individual users' needs, easy to repair and reasonable priced.

#### Collaboration between manufacturers

Establish collaboration on national level between different workshops for importing material and parts in lager quantities in order to reduce costs and improve quality. As a result of the 3<sup>rd</sup> African Wheelchair Congress organised in Zambia in August 2003, Association for the Physically Disabled in Kenya (APDK) in Kenya suggested establish a collaborating network between the African countries in order to reduce the costs of imported wheelchair components and thus increase the quality of wheelchairs and tricycles.

#### Introducing new wheelchair design

Introducing the new WWIP wheelchair model would be a fruitful way of strengthening existing local workshops manufacturing wheelchairs and tricycles. This should be followed by capacity building focusing on knowledge about:

- □ Assessment identifying user needs
- □ Adapting the wheelchair to fit both the user's individual needs and the environmental demands
- □ New design and adaptations of wheelchairs and tricycles for children
- ☐ Training of the user including family and careers in order to do basic maintenance and to follow up the mobility device



Photo: Ms. Sharifa Mirembe, Made testing the new WWIP wheelchair mode, Ultralight

Organising repair, maintenance, assembly and manufacturing of wheelchairs and tricycles
The production might be organized as a hierarchy whereby service, repair, follow up of the
user and manufacturing of simple assistive devices might be done at the community level.
From the local community level the users could be referred to district level and regional level.
It is important to establish awareness and knowledge about provision of assistive devices out
in the communities where most of the people are living their daily lives.

Further investigations could be made together with local representatives (users/existing manufacturers) in order to clarify whether manufacturers like RoadMaster or others could become collaborating partners manufacturing vital parts. As an example the frame might be manufactured in larger quantities, ensuring equal quality at a lower price. The frames could then be handed over to the local workshops in both Kampala and out in the districts.

#### 8. Abbreviation

MoH – Ministry of Health

MoGLSD - Ministry of Gender, Labour and Social Development

NGO – Non Governmental Organizations

PWD - People with Disabilities

**DPO - Disabled Persons Organisations** 

UN - United Nation

NUDIPU - National Union of Disabled Persons of Uganda

NAD - Norwegian Association of the Disabled

MADE - Mobility Appliances by Disabled Women Entrepreneurship

ICF - International Classification of Functioning, Disability and Health

WHO – World Health Organization

TATCOT – Tanzanian Training Centre for Orthopaedic Technologists

APDK - Association for the Physically Disabled in Kenya

WWI – Whirlwind Wheelchair International

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# 10. Appendix 1: Report of a Meeting on Wheelchair Production held on Friday, 14 November 2003 AT NUDIPU Offices

#### 10.1 Background Information

The meeting was intended for presentation of findings of a feasibility study conducted in Uganda with regard to wheelchair production by a team from the Norwegian Association of the Disabled (NAD) in collaboration with Whirlwind Wheelchairs International to possibly boost wheelchair production in selected countries. The study was scheduled to commence on 10<sup>th</sup> and end on 18<sup>th</sup> November 2003. The major aim of this study was to create the best possible background for determining whether a wheelchair production project is feasible or not, and then organise a programme depending on the findings. The process for this feasibility study was coordinated by Disability, Prevention and Rehabilitation (DPAR) Ministry of Health.

#### 10.2 The Meeting

The meeting was hosted by the National Union of Disabled Persons in Uganda (NUDIPU) at their offices in Bukoto - Kampala Uganda. Twenty-three people attended this meeting. (Attendance List attached as Appendix).

#### First Part of the Meeting

Mr. Fabiano Opira, Administrator of NUDIPU chaired the first part of the meeting. He welcomed members to NUDIPU and then requested Ms. Barbara Batesaki to give a word of prayer. He later guided members through the introductions and expectations.

#### <u>Introduction and Expectations</u>

The introduction process was conducted concurrently with members' expectations. Below are the expectations given by members:

#### Expectations

- Feasibility plan for the production of wheelchairs for the African continent.
- The whole life cycle of the wheelchairs (production, adjustments, marketing, etc.)
- Hear about the results of the feasibility study and about appropriate technology.
- Get knowledge about production, availability, suitability and affordability in regard to wheelchairs.
- Suggest suitable place for production of wheelchairs.
- Get results for feasibility study and give relevant advice e.g. wheelchair laboratory.
- New knowledge about wheelchair design.
- The long-term problem of wheelchair production and distribution.
- Ideas to develop affordable and more dependable wheelchairs.
- Gain an overview of the situation of persons with disabilities using wheels.
- Recommendations with regard to production and distribution.
- Find a way oftodevelop a new wheelchair in Uganda.
- See the strength of wheelchair production in Uganda and find ways that persons with disabilities will be able to access the wheelchairs.
- Promotion of a component of wheelchairs in regard to wheelchair use and production.

- To set a strategy for the distribution of wheelchairs in the community.

#### Meeting Objectives

A representative of the feasibility study team, Mr. Svein Brodtkorb, was given an opportunity to give clarity in regard to the objectives of the meeting. He informed members that the team had only carried out the study within institutions and workshops around Kampala and Jinja and had yet to visit the rural areas. He mentioned that they were to visit Tororo and Mbale on 15<sup>th</sup> and 16<sup>th</sup> November 2003 respectively. Therefore, since the team had not completed the study they were not in position to present the findings. He further clarified to members that this particular meeting was to be part of the study report, which will be availed to members.

Mr. Brodtkorb went ahead to give background information regarding the study. He mentioned that the whole process was initiated in 2002 when NAD and Whirlwind Wheelchair International participated in a process of improving wheelchair production in Norway. He emphasised that the major aim of this programme is to produce wheelchairs, which are durable and user friendly. He further noted that NAD has programmes in different countries in Africa but selected to carry out the study in Uganda because of the presence of a strong disability movement. He also stressed that to ensure that the programme is relevant to Ugandans, emphasis will be put on building on the existing wheelchairs which will involve linking up with organisations involved in production of wheelchairs to ensure ownership.

Therefore noting that there were no results to be presented members agreed to discuss wheelchair production under the following headings:

- Production of wheelchairs
- Marketing, distribution and financing
- Fitting
- Environment and adaptations
- Continuous maintenance

#### The Second Part of the Meeting - Discussions

Ms. Barbara Batesaki, a Senior Physiotherapist, Disability Prevention and Rehabilitation Ministry of Health chaired the second part of the meeting, which comprised of discussions according to the above headings. She was also the secretary to the meeting.

#### **Discussions**

The discussions were conducted in such a way that the chairperson introduced the topic, which was followed by a comment / keynote by the study team and later an open discussion by members.

#### Production of Wheelchairs

#### Keynote

Mr. Ralf Hotchkiss of Whirlwind Wheelchair International informed members that the team had visited different workshops involved in production of wheelchairs around Kampala and Jinja. He noted that during their visits they realised that the most commonly manufactured wheelchairs were the tricycles and the Huckstep wheelchairs.

#### Key Issues highlighted:

Although many people prefer using the tricycle it does not mean that the foldable wheelchair is not needed. The foldable wheelchair can enable persons with the more significant disabilities to access different facilities easily.

Each wheelchair user needs relevant adjustment.

The Huckstep wheelchair, though greatly criticised these days, was a great input at that time when it was introduced. This wheelchair is recognised in the world today as the strongest, most durable and long lasting. The major strength about this wheelchair is that repairs are locally available.

Mobility Appliances by Disabled Women Entrepreneurship (MADE) used the Huckstep idea to make a wheel chair that would cater for those with spinal cord injuries and other significant disabilities of higher levels.

Key issues noted during the discussion:

Level of transfer from the bed to the chair -A representative from MADE explained that this depends on the disability and relevant adjustments are made accordingly. She gave an example about the armrests, which are designed differently and these may be triangular, round or rectangular. She also informed members that MADE started developing an improved wheelchair in 2000 putting into consideration the transportation issue from one district to another.

A number of wheelchairs have been received from the Lions Clubs and Rotarians through the Disability, Prevention and Rehabilitation in the Ministry of Health.

A lot of money has been spent on the importation of wheelchairs. In most cases these imported wheelchairs are not suitable for the Uganda terrain. Also repairing these imported chairs is very difficult as spare parts are not on market in Uganda.

Whirlwind Wheelchair International used locally available materials and technology and also involved persons with disabilities in the production of the wheelchairs.

At a recent congress for wheelchair users held in Zanzibar, quality came out as a major issue of concern.

The tricycle has the facility to enable the user to carry items with her or him yet the other wheelchairs lack this facility.

There is need to identify the level of disability and then make a chair tailor-made to suit the needs of the individual. Each wheelchair should suite the disability, and enable the user to carry on their occupation.

The majority of people with the more significant disabilities do not even have access to wheelchairs. There is an urgent need to identify ways and means to enable people with these disabilities to access wheelchairs.

One member suggested that if the programme for developing wheelchairs takes off the target group should be 0-19 years. This is because this age group can appreciate change. But any person beyond 19 years will not accept change, if he is already used to crawling it is not easy to get him / her to use a wheelchair.

There is need for orthopaedic laboratories in the villages or regions.

Although many people are involved in wheelchair production most of them are not following standard guidelines. Most important is that prescriptions for wheelchairs should be made by the right people.

Adaptations should be made to ensure that mothers and fathers using wheelchairs can move easily with their babies.

For proper maintenance of the wheelchairs there is need to train local people in doing simple repairs.

#### **Fitting**

#### Keynote:

The Chairperson noted that fitting is understood differently by the different people involved in the production of wheelchairs, for example; to the technicians it is the fitting of the different components. To other professionals such as the physiotherapists and occupational therapists it is about the various adjustments depending on the disability of the user. She gave an example of a child with cerebral palsy who may be very spastic and his / her leg just straightens out. in this case the solution would, in most cases, be to adjust the seat so as to break the abnormal pattern. Yet for a parent without relevant sensitisation the immediate idea would be to tie the leg to prevent it from straightening.

Key issues noted during the discussion:

- Standardising sizes of wheelchairs in the workshop would ease production.
- Taking proper measurements to ensure individual fitting is very important.
- There is need for standardised components.
- Prescriptions should be given by the right people.

Some companies are just involved in mass production of wheelchairs without considering the individual needs of the user and this at times results in disabling the user further. An example is Roadmaster, a company making bicycles and also involved in manufacturing wheelchairs was given; During the visit to Roadmaster the study team found 800 wheelchairs which had been made but with a wide fitting between the tyres and the seat, making it strenuous to reach out to the hand rims to move the chair.

It was suggested that the Disability, Prevention and Rehabilitation Section Ministry of Health discuss meet with Roadmaster about making the necessary adjustments tp these chairs.

There are many social, economic and political issues related to production and distribution of wheelchairs to the poor people in the community. Most of them receive these wheelchairs out of charity, at times from politicians who want to help their people, so they just contact the producers to give them wheelchairs whereby the producer gets no opportunity to take measurements. As a result of this, the user often never uses the wheelchair because it does not fit and it may cause more problems.

#### Environment

Key issues noted during the discussion:

- The terrain in some parts of Uganda like Kabale, Kisoro, Mbale, Sironko and Kapchorwa is not favourable for wheelchair use.

- Most of the buildings in Uganda are not accessible to persons with disabilities. It was noted that with continuous sensitisation a number of new public buildings have provisions for wheelchair users.
- Although some buildings have ramps, a number of them were constructed poorly. Their architects never used proper measurements of slopes, widths, or other critical factors..
- Issues regarding accessibility are included in the Disability Act.
- The Universal Primary Education (UPE) Policy is very clear in regard to accessibility. NUDIPU disseminated information to Ministry of Education and Sports for proper design of classrooms which were being constructed under the UPE programme. Despite all the efforts made by NUDIPU it was realised that in some places what was done during construction was quite different. It was also noted that in some districts the specifications for proper ramps came in quite late.
- The beds in labour suites, particularly in rural areas, are not accessible to women with disabilities who use wheelchairs.

#### Marketing, Distribution and Financing

Issues noted during the discussions:

Marketing of wheelchairs is difficult. It was noted that although many people are crawling, most of the local initiatives making wheelchairs especially at a low scale do not get buyers.

The majority of people who need wheelchairs cannot afford the cost or even afford the repairs.

Mulago Orthopaedic Workshop used to produce 200 chairs per month but now the production has reduced greatly.

#### 10.3 Recommendations and the way forward

All technicians involved in wheelchair production should receive relevant training.

Wheelchair components and relevant adaptations should be standardised.

A Policy on production of wheelchairs should be put in place.

Standards and guidelines for production of wheelchairs should be strictly followed.

There is need to develop a system for marketing wheelchairs.

Prospective wheelchair users to have a medical report (Assessment).

All wheelchairs should have reflectors.

Capacity building for all stakeholders should be given high priority as indicated below: Sensitisation for the following:

- Producer, community
- User, parents
- Donors
- Politicians

Training for the following:

- Community workers
- Artisans
- Medical service providers
- Relevant training for the different people

The latest designs should be made available to the producers.

Disability Prevention and Rehabilitation Section to advise Roadmaster accordingly.

Promote attitude change towards wheelchair use e.g. through campaigns.

Improve communication and management.

Clear data should be collected in regard to wheelchair use.

A Database on wheelchair production and use should be developed.

#### **10.4 Conclusions**

The meeting ended successfully, but noting that the time allocated to this meeting was short it was agreed that any other issues of concern could be communicated to the chairpersons whose e- mail addresses were given to members.

#### 10.5 PARTICIPANTS - REGISTRATION FORM

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