### 4<sup>th</sup> ALL AFRICA WHEELCHAIR CONGRESS REPORT

### **17<sup>TH</sup> – 21<sup>ST</sup> SEPTEMBER 2007**

### UHURU HOTEL, MOSHI TANZANIA



Theme: Advancing Appropriate Wheelchair Services for Africa

Hosted by:

### The Pan Africa Wheelchair Builders Association (PAWBA) and The Tanzanian Training Centre for Orthopaedic Technologists (TATCOT)

SPONSORS:WHO, USAID, ABILIS, CBM, SINTEF, TATCOT, MOTIVATION AND WWI

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#### **EXECUTIVE SUMMARY**

The 4th All Africa Wheelchair Congress under the theme "Appropriate wheelchair services for Africa" was conducted from  $17^{\text{th}} - 21^{\text{st}}$  September 2007 at Uhuru Hotel Moshi Tanzania. The opening was graced by guest of honour, Dr Zakaria Berege the director of health services from the Ministry of health and social welfare (Tanzania) who represented the Minister.

The main Objective of the Congress was to foster collaboration, disseminate learning, and establish appropriate as well as professional wheelchair services that address the real needs of the users in a professional, co-ordinated and sustainable way in view of improving the quality and quantity of appropriate wheelchair services across the continent.

PAWBA and TATCOT were the facilitators of the congress and the Co-funders included the World Health Organisation, ABILIS, Motivation Africa, Christoffel Blindenmission (CBM), and SINTEF.

The Congress gathered 116 members from Sierra Leone, Nigeria, Sudan, Ethiopia, Uganda, Kenya, Tanzania, Angola, Malawi, Zambia, Zimbabwe, Namibia, South Africa, UK, Norway and USA.

Main Topics covered included Impact of wheelchair on quality of life, Partnership for Appropriate wheelchair services (Global and African perspective), Wheelchair Technology Training, Wheelchair services and poverty reduction strategy, UN,WHO,ISPO standards, Conventions and Guidelines, Capacity building and managerial skills in wheelchair provision, Professionalisation of wheelchair services and the scale of the need in Africa, Network of organisations involved in production and distribution of wheelchair services.

#### The congress made the following resolutions:

- PAWBA to ensure that affiliated workshops distribute wheelchairs as provided in the WHO guidelines.
- PAWBA to lobby governments to adopt minimum wheelchair standards.
- To encourage regional production where it brings in economies of scale.
- PAWBA to engage with other Pan African initiatives or groupings like ARI, the Africa Decade Secretariat, Africa Development Bank, COMESA and other economic and political groupings to bring issues of wheelchair services to the African agenda.
- Wheelchair Services to work in collaboration with DPOs and be sensitive to the unique needs of the users.
- PAWBA to ensure equal opportunity in participation in its structures.
- To seek affiliation to internationally recognised associations.
- To lobby governments to recognise the Wheelchair Technologist Certificate course.
- PAWBA to explore possibilities of centralised purchasing.
- To support research and development to improve product quality.
- TATCOT be asked to speed up the process of upgrading the certificate course to a diploma.
- The name of the organisation to be changed from Pan African Wheelchair Builders Association (PAWBA) to Pan African Wheelchair Association.
- WWI and Motivation be co-opted into the Executive Committee of PAWA to strengthen the work of the organisation.
- That standard designs be developed to help producers develop appropriate chairs.

### Background information

Previous All Africa Wheelchair Congresses have taken place in Zimbabwe (1995), Kenya (1998) and Zambia (2003); each has been a major landmark in the development of appropriate and affordable wheelchair products and services, providing valuable knowledge-dissemination opportunities to stakeholders from across Africa.

The 4<sup>th</sup> All Africa Wheelchair Congress continued this tradition and provided a variety of stakeholders involved in wheelchair provision with an opportunity to demonstrate:

- The positive role that appropriate assistive technology plays in poverty reduction and enhanced quality of life
- the significance of appropriate mobility to achieving empowerment and accessing equal rights
- the importance of the professionalisation of wheelchair services to the user, addressing their mobility needs in a responsible way
- the ways in which improved mobility enables participation that influences positive attitudinal change towards disability and inclusive policy development.

In 2003 the Congress participants formed the Pan-African Wheelchair Builders' Association (PAWBA) as an internationally representative, non-governmental, membership network to facilitate learning exchange and to provide practical guidance and professional support to its membership across Africa.

PAWBA's <u>Vision Statement</u>: To empower people with disabilities, socially and economically, through the provision of mobility aids.

PAWBA's <u>Mission Statement</u>: Every person with a disability in Africa in need of a wheelchair will be provided one of appropriate design and of good quality.

Prior to the 2007 Congress PAWBA had appointed a Coordinator and a Board; completed official registration in Tanzania; established an office at TATCOT; secured a grant from Motivation UK as part of a USAID-funded programme to support wheelchair services, and begun to implement a programme of activities, including the planning of the 2007 Congress.

A summary of each of the Congress sessions is provided below, as well as a list of resolutions that were agreed as part of the PAWBA General Meeting on the final day of the Congress. In addition, it was agreed to change the name of PAWBA to PAWA – The Pan African Wheelchair Association.

### DAY 1: Monday 17 September 2007

### Theme: Disability rights and wheelchair services

### Introductions

Introductions of the participants was led by Mr Aston Ndosi, who went on to announce congress logistics and administrative facilities.

### Welcome Remarks by David Mukwasa, Chairman of PAWBA

David Mukwasa welcomed the delegates and then proceeded to introduce the Guest of Honour and Special Guests.

### 'Disability Rights: Global and African Perspective', Khalfan Khalfan

Khalfan informed the delegates that the conference coincides with signing and ratification of United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and has the potential to contribute to the aims of the Convention. He went on to point out that:

- There are challenges facing all countries in terms of mobility and transportation, and that accessible transportation in developed countries is a result of groups working in those countries.
- Estimates suggest that there are 650 million people with disabilities across the world; 190 million of whom are children; 86 million are in Africa.
- By 2025 there will be 900 million people with disabilities; 650 million in developing countries alone.
- Recent World Band report shows strong correlation between poverty and disability.
- UNCRPD marks a paradigm shift in treatment of people with disabilities from recipients of charity to rights holders.

Khalfan went on to point out that Article 9: of the Convention mentions Accessibility, the first time that accessibility has ever been mentioned in a convention. Article 20 is on personal mobility. Bestowing rights is not enough: rights holders must be able to access those rights. There is a need for a speedy ratification of the convention if it is to have an impact on the lives of disabled people.

Khalfan went on to state that:

- The African Decade of Disabled Persons 1999-2009 has been formed to raise awareness of disability issues in the region and to create solutions to the problems.
- Programmes and projects for people with disabilities are needed to aid development and wheelchair workshops need to be committed.
- Workshops should also increase production, reduce cost and improve solutions by sharing solutions to common problems and liaising with other countries.
- Donated wheelchairs are not a sustainable solution to those who need wheelchairs, and they need appropriate wheelchairs, and governments

need to have a well developed policy regarding the technical elements of wheelchair design, production and distribution.

• Over the past few years, minor improvements have been made but we continue to be disabled by the environment

Mr Khalfan concluded his presentation by pointing out that at PAFOD, and its affiliated structures to grassroots levels they have channelled energies to influence and liberate the lives of 650 million people with disabilities. He called on PAWBA and the wheelchair workshops to work together to influence change in the provision of services.

### 'Report and Resolutions from the Bangalore Wheelchair Consensus Conference', Joe Obiedo, World Health Organisation (WHO)

Mr Joe Obiedo of the World Health Organisation, presented a summary of the outcomes of the Bangalore Wheelchair Consensus. He stated that the Conference managed to come up with a draft definition of an appropriate wheelchair which was presented as:

### A wheelchair is appropriate when it is safe, durable and maintainable, meets the individual's needs and environmental conditions, provides proper fit and postural support based on sound biomechanical principles and can be accessed and sustained at the most economical and affordable price.

He went on to say that the conference also came up with the following:

- The importance of user involvement in wheelchair provision.
- Lack of accurate estimate of the number of people who need a wheelchair.
- Information sharing: the need to share information among countries
- Defined minimum technical requirements of an appropriate wheelchair according to ISO standards, which should be met or exceeded.
- Considerations needed when distributing wheelchairs.
- Training and education as key elements of wheelchair provision.

### 'Remarks', Professor Shao, Executive Director KCMC

Prof. Shao welcomed delegates to the Congress and to Moshi and wished them a fruitful stay. He said that every three years there is such a conference to facilitate the sharing of ideas and experiences and went on to congratulate the PAWA committee for choosing a relevant theme. He urged the congress to update information on areas that still need addressing in low-income countries.

Wheelchair users have been largely ignored up until now. We therefore need to remind ministries, leaders of institutions etc, that it is now their obligation to meet the needs of disabled people.

Prof. Shao noted that wheelchair provision has failed to develop at the same rate as prosthetics and orthotics, but pointed out that various wheelchair training courses now available are commendable, and that there is a need to increase the number of institutions that conduct such courses. He urged the delegates to develop strategies that will liberate people with disabilities, and to follow up on these.

# 'The Relevance of PAWBA in the next decade', David Mukwasa (PAWBA Chairman)

Mr Mukwasa, thanked the speakers for providing key addresses and giving the participants information that will help in defining the future agenda of wheelchair services. He said that DISACARE Wheelchair Centre in Zambia has observed great changes in the development of wheelchair production and services in the past two to three years. It is increasingly competing with mass production and distribution, which is not always appropriate.

It is not acceptable to deliver any wheelchair to any one, it must be fitting to the user in the same manner that a shoe does. He pointed to the importance of government involvement in wheelchair production and services to ensure a sustainable service. He urged the guest of honour, Dr Zacharia Berege to encourage other governments in different countries to get involved in local wheelchair production.

Mr Mukwasa congratulated Motivation and Whirlwind Wheelchair International for the training that they have provided in Africa, and encouraged Wheelchair manufacturers to build their organisational and technical capacity to be able to increase production and keep standards high. PAWBA is a coordinated body with more relevance in the coming decades because it will be able to coordinate between countries, bringing initiatives such as:

- o central purchasing
- o links with government officials
- o fundraising support for workshops

Mr Mukwasa thanked all funders who made it possible for so many people to be at the congress, and then invited Dr Zacharia Berege to officially open the conference.

# 'Official Opening', by guest of honor Dr Zacharia Berege, (Director of Ministry of Health and Social Welfare – Tanzania)

Dr Berege apologised for the Minister of Health who was not able to attend due to other commitments. He welcomed all the delegates to Tanzania and congratulated the founder members of PAWBA. He observed that in Africa less than 2% of people who need wheelchairs have them according to UNESCO. He noted that most national development plans in Africa have limited reference to people with disabilities and therefore awareness creation is key to highlighting the problem.

He advised that the delivery of wheelchairs should not exceed the infrastructure of the local community to support those wheelchairs to ensure that quality is maintained. There was therefore a need to create more awareness of the World Health Organisation Guidelines for Wheelchair Provision in Less Resourced Settings and the government will be willing to receive proposals on how to improve life for PWDs.

Dr Berege, then declared the 4<sup>th</sup> All Africa Wheelchair Congress officially open at 11:10AM.

The guest of honor then led a group of special guests to view the exhibits of mobility aids from various countries in Africa.

# Role of the International Society of Prosthetics and Orthotics (ISPO) in wheelchair development, Harold Shangali (Immediate Past President ISPO)

Mr Shangali gave the introduction on the formation and objectives of the International Society for Prosthetics and Orthotics (ISPO). Founded in 1970, it focuses on Multidisciplinary professional interests in rehabilitation, engineering, orthotics and prosthetics and currently its membership is 3,000 worldwide. The key activities include education & training, consensus conferences, publications.

There are regular reviews of Technology and Service Provision to people with disabilities. In Africa technology was initially centred on donated technology. Surveys were carried out to review technology and service provision in East Africa and strategies were developed on production techniques, locally available materials and resources, and training needed. This led to the establishment of the Wheelchair Technologists Training Course (WTTC) at TATCOT, establishment of PAWBA etc. Wheelchair workshops have been established and now need to have improved infrastructure.

ISPO got involved with wheelchair issues in 2004 and have accredited the WTTC and will continue supporting training and education. The agreement on the WHO Guidelines will help to standardize training, services and quality. The future strategies in wheelchair provision are therefore to:

- Finalise guidelines
- Develop short term modules in training
- o Setting standards

Concluding his presentation Mr Shangali highlighted the following needs:

- Promoting the wheelchair profession among governments and NGOs.
- Wheelchair builders to form part of recognised rehabilitation team.
- o Enhance wheelchair builders, clinical and technical skills.
- Get PAWBA to network internationally and to charge membership for financial sustainability.
- Develop PAWBA's strategy for the future.

'Disability Rights and Wheelchair Service - African Perspective', AK Dube (The African Decade Secretariat)



Mr Dube introduced himself as a new member of the African Decade Secretariat which is based in Cape Town, South Africa. Dube noted that assistive technology has not been well addressed in the disability movement in Africa despite being essential for disabled people to access their rights. He said disabled people's rights are the same as human rights, such as the right to transport services; mobility; community living. He pointed out that at country level policies and legislation that support access to and financing of wheelchairs are either not there or very weak to be of any use. There is need to produce locally and to campaign for local buying. Replacement of inappropriate donated wheelchairs can only happen if there is quality production locally.

Assistive Devices enable individuals to access their rights and the ideal situation is where research and development are user led, there is government support, viable production facilities and vigorous marketing campaigns to reach across borders.

Dube concluded his presentation by saying the way forward should include:

- Financial sustainability models need to be worked out.
- A strong campaign to provide political and administrative support.
- o Effective wheelchair distribution system.

# Wheelchair Service Presentation from Lorewo in Zimbabwe by Alec Mateya

Mr. Mateya, a technologist working with LOREWO in Bulawayo gave a summary of the work of the workshop. He informed the participants that

LOREWO was established in 1999, with the objective of producing wheelchairs that are affordable to disabled people.

He went on to acknowledge the support the workshop was getting from SINTEF, TATCOT and Motivation.

### 'Wheelchair Service Provision from CARE Kenya', Nancy Mbugua

Ms Mbugua pointed to the need for more wheelchair technologists as there was a demand for appropriate wheelchairs. She pointed to the need for education on what an appropriate wheelchair is so that governments and other stakeholders involved in wheelchair services know the importance of a wheelchair to the beneficiaries.

# 'The Suitability of Wheelchairs from industrialised countries', Nicky Seymour (Motivation)

'Is anything better than nothing?' This is the question Nicky Seymour opened her presentation with, a juxtaposition of a situation of giving a wheelchair to the next person who needs a wheelchair or giving a person an appropriate chair. She acknowledged the extent of the need, particularly in Africa, but emphasized the need to move towards a professional service in wheelchair distribution. She pointed out that there are four key areas to consider:

- Adjustability: Does the chair fit the user? Does it come with a pressure relief cushion?
- Suitability: Can the chair access the local terrain?
- Durability: How long will the chair last?
- Sustainability: How will wheelchair users get chairs in the future?

### Poverty and Disability: The Facts, Tone Øderud (SINTEF)

Tune Øderud, observed that 10% of the global population are disabled, and that 80% of people with disabilities live in low-income countries according to the United Nations. 150 million children with disabilities lack access to child care services, schools, recreation and other social services. Disabled people make up 15-20% of the population of poor people in developing countries, but the support services remain very low and that makes it difficult to break the poverty circle.

### Wheelchair options for Africa. Aron Dilu – TATCOT.

Mr Dilu observed that there are various definitions of a wheelchair but the most important one for TATCOT is the one which came from the ISPO / WHO Wheelchair Consensus Conference which states that:

A wheelchair is appropriate when it is safe, durable and maintainable, meets the individual's needs and environmental conditions, provides proper fit and postural support based on sound biomechanical principles and can be accessed and sustained at the most economical and affordable price. He pointed out that TATCOT has invested in the design of wheelchairs that are durable and can be adapted to the needs and size of the user. TATCOT is also training the students on wheelchair production to ensure that there is an increase of skills to produce them locally.

In concluding his presentation he pointed to the need for a service that ensures that an appropriate wheelchair is issued after a process of assessment fitting, prescription, training and design alteration and that government and all stakeholders should play a role in ensuring standard procedures in wheelchair provision services.

### 'A wheelchair is a basic human right', Francesca Garton (Motivation)

Ms Garton described a wheelchair as a human right because it enables one to be mobile, and mobility is a basic right. A wheelchair enhances a users functional abilities giving them personal mobility.

She went on to say that only 5-15% have access to wheelchairs in lowincome countries. Local production is limited or non-existent in most places.

She outlined three models of disability as:

- Charity model: views disabled people as beneficiaries of charity, to be grateful. Disabled people can become dependent on the whims of those 'giving'.
- Medical model: where society views disabled people as having 'problems' that need to be cured. Focuses on so called 'normal' people 'curing' people
- Social model: views society as having social and physical barriers to disabled people. A disabling world.

A rights based approach is a user-focused approach where wheelchair users themselves can campaign for inclusion and are participants in deciding the type and design of an appliance that they want.

She went on to say that the UNCRPD which was adopted in 2006 outlines mobility as an important aspect of life in article 20.

### **Plenary Session: Discussion on the Sessions**

**Gladys Charowa** – Director of the Disabled Women's Support Organisation of Zimbabwe - There is a need for more women in the leadership of PAWBA. **Piet de May** – (Working with the Angola Government). The resources are limited and a lot is being put in other challenges like diarrhoea and malaria. If we talk like this (harshly) to government they won't consider us seriously. We have to change our thinking if we want to get money from government. We should also think about exporting so that we can sell and give wheelchairs to people who can't afford.

**AK Dube** – African Decade of Disabled People. Totally agree that we need to be strategic in the way we communicate our message in a manner that will bring results. So we need to use different tactics for different situations. However I disagree with the thinking that we should be apologetic when we

ask for rights. If they are rights enshrined in the convention adopted by that country it is our right to ask for them.

One participant suggested that the workshops should begin to think about making electric wheelchairs for people who can afford them.

**Kenny Mubuayeta** – DISACARE Zambia– I am in support of the TATCOT presentation – they are talking of something that satisfies the needs of the user. If you look at most imported wheelchairs they are not appropriate. We are also looking at improving the clinical side of the wheelchair. Mostly when the donations come someone has given them without thinking about assessment, prescription and fitting. It needs to fit the physical and environmental needs of the user.

**Owidi Alfred** – Government Services Uganda. People get wheelchairs from wheelchair foundation and distribute to their clients. What strategy can we use to change the attitudes of people who are distributing these wheelchairs so that they consider appropriateness to the user? The technologists who are in Uganda are spread around the country. The major centre which is the national referral hospital has only one technologist.

**Nancy Mbugua** – Care, Kenya. Kenya has only one wheelchair technologist. The government have not recognised the profession of wheelchair technologists. Mr Seifert is working with the government of Kenya but I would suggest that the government is encouraged to recognise wheelchair technologists. This is a challenge to all of you – if wheelchair technologists are not recognised in your countries then lobby for recognition.

**Tone Øderud** – Sintef, Norway. In Norway every disabled person in need has the right to a mobility device. But you don't own the device, you give it back when you need a new one. I would encourage all the stakeholders here to push all the Ministries to recognise the rights of people with disabilities. We have done that in Norway and everyone has played their role and now after 30 years we have a much better situation.

**Khalfan Khalfan** – On the issue of rights, how many disabled people understand their rights? How far do we share the knowledge and understanding of rights to people with disabilities – particularly those in rural areas. Look at the people at grassroots – do they understand their rights? DPOs have to take responsibility of providing this knowledge of making people with disabilities understand their rights in terms of wheelchairs, education, People don't know – we are only talking at a higher level – Most of the work needed is at the grassroots level.

Prevalence of statistics – disabled people were not involved in the census. Enumerators were not trained to understand who is a disabled person. People who are deaf, of have invisible disabilities. We need to work together to do scientific surveys.

**Shona MacDonald** – Shonaquip South Africa - Model in South Africa – we fought extremely hard for our rights, and in South Africa everyone in South Africa has a right to a wheelchair. The way the government provides services for its people is in relation to its level of development. Some countries find funds for wars but not for its people.

**John** – APDK Kenya – we are trying to come up with the right tricycle in Kenya, and looking for locally available materials. You can't say something is better than nothing. I ask PAWBA to advocate that no wheelchair should be imported into Africa without the approval of PAWBA. I don't think you can say you only have funds for malaria – the disabled person has the right too.

Adolphus Okeke – O Dolf Ltd Nigeria – Disability Rights – Wheelchair users who are in the house hidden cannot fight for their rights - we need to get wheelchairs to them.

**Isaac Nyathi** – Chairman of session – There is still a lot of discussion needed on the issues that have been raised such as motorised chairs, inclusion of women, advocacy to Governments. These discussions should continue in corridors and am sure we will pick some of them as we go on with the congress. Thank you.

### Day Two: Tuesday 18<sup>th</sup> September

### Theme: Partnerships for appropriate services

### Wheelchair service presentations:

### POC, Ethiopia

Denu Hailemarium explained the different clients that POC serve and services they offer in Ethiopia. They produce a range of products locally including 3 wheelers, 4 wheelers and children's wheelchair.

### Shonaquip, South Africa

Shona Macdonald started by describing the situation in South Africa; diverse issues, big disparity of services. She went on to explain some of the history of service provision in Cape Town for the entire country's service provision programme. Lobbying government continues to be an important part of their work, proving their arguments with researched statistics. Training and awareness raising about the needs of people with disabilities and the services and products they need to all levels. Encouraging formal collaboration between stakeholders. Donor fatigue is a big risk, and ultimately government needs to take responsibility and lobbying should continue. Their model is one of team work in all areas.

### DISACARE, Zambia

Kenny presented a brief history of DISACARE; formed in 1991 by a group of disabled people to produce wheelchairs and other appliances. The products include an 'ordinary' model of wheelchair (Africa 1), CP wheelchair (adapted Africa 1), Tricycles, basketball wheelchair, bicycle ambulance, motorbike ambulance (prototype) and offer wheelchair repair services. DISACARE also offers training in wheelchair building and repairing.

Kenny went on to show a series of photographs of DISACARE's work; their wheelchairs, some people with some serious postural deformities which challenged them, their tricycle, and sports wheelchairs. The new product this

year is a tennis wheelchair funded by international wheelchair tennis federation and went on to show the first WWI Rough Rider that they built recently and explained some of its features and advantages.

# Understanding user needs (Partnerships for Appropriate Services) – Henry Nyamubi (KASI)

Henry started by briefly presenting some facts about the need for wheelchairs, particularly that it is estimated that over 100,000 people with disabilities in Tanzania are in need of wheelchairs. He went on to explain some of the main issues for people with SCI and denial of basic rights and the serious harm that inappropriate wheelchairs can cause. He pointed that understanding user needs helps to improve access to better services, set standards and benchmarks. The users needs were listed as:

- attractive wheelchairs (part of one's personality),
- sitting comfort,
- indoor and outdoor use,
- safe and easy to propel,
- easy to transport,
- easy to repair locally,
- suited for long distances
- affordable.

He then recommended to wheelchair builders, that wheelchairs should be; adjustable, affordable, suitable, durable, sustainable, variety of models (choice) and appropriate services that are in line with the WHO/ISPO wheelchair consensus conference definition of an appropriate wheelchair.

**Question**: one participant asked whether enough was being done to market products properly and if marketing methods were part of the training for the technologists.

**Answer**: Kenny responded that PAWBA should do more in the area of marketing because this is DISACARE's greatest challenge. He asked what PAWBA can do to support them to lobby government and attract Physiotherapists to work in this field.

### Wheelchair service presentations:

### O Dolf Ltd, Nigeria - Adolphus Okeke

Adolphus started by giving some background about O Dolf Ltd. He went on to explain some of the main issues of wheelchair production in Nigeria where the cost of production is very high. Though there are workshops that produce wheelchairs they do it without being aware of the impact of an inappropriate wheelchairs. Largest challenge is to raise awareness about appropriate wheelchairs and inform wheelchair users of the dangers posed by inappropriate wheelchairs.

### Working with DPOs – Henry Nyamubi (KASI)

Henry started by describing how most DPOs start; by the solidarity of self help groups who come together to support each other through their common hardships. Henry went on to explain why people form DPOs, their role and importance of the main work of DPOs. Disability is a rights issue; 'Nothing About Us Without Us' is very relevant to the advancement of disability services in Africa. DPOs are well placed to work with other stakeholders to create partnerships to advance services. DPOs are advocating for a rights based approach – to ensure that service provision is appropriate to people's needs and is availed as and when needed.

Since 1981 the Tanzanian government recognised DPOs as forums that represent disabled people's needs and are the best source of support and information for disabled people. Sometimes there are tensions between professionals and DPOs; sometimes there are conflicts of interest. Some rehabilitation professionals dismiss the value of engaging with the disability movement at the risk of alienating DPOs because of control of the rehabilitation process. From the other side some DPOs are reluctant to partner with rehabilitation professionals because of a lack of capacity and uneasiness that the underlying philosophy of rehab puts the power into the hands of professionals. However we should form partnerships to empower disabled people, entering into genuine mutual consultation, involve DPOs in the design and implementation of programmes to promote a clearer understanding of the issues. The key to a rights based approach is that disabled people should participate fully in all areas of production and service provision.

Henry finished by explaining some background of KASI which was established in 1991 to promote the rights and welfare of people with SCI.

# Legislation on Disability and Wheelchair Services: different country presentations:

### Malawi

Robert Nyirenda presented the Wheelchair Situation in Malawi. Although there is currently no legislation regarding mobility appliances, the government is committed to the provision of locally produced appliances and has trained six wheelchair technologists and production will start soon. Robert explained that there are organisations producing mobility products but they lack capacity and expertise and their products are expensive. Rotary clubs and other charitable organisations donate and distribute imported, inappropriate wheelchairs.

The Malawi government's road map is to establish a wheelchair workshop and service to provide appropriate wheelchairs, provide supportive seating, provide maintenance and repair.

### Sierra Leone

The presenters from Sierra Leone were three wheelchair technologists who graduated from TATCOT. The first presenter explained that statistics for disability recently collected in the census were alarming. 4.9 million people of which 6% have disabilities. The conflict has caused many disabilities for men, women and children. The prevalence of cerebral palsy is very high. In 2005, 3 wheelchair technologists were nominated by Handicap international (HI) and sponsored by InWent to attend the WTTC at TATCOT. Before the graduates returned there were no wheelchair services in Sierra Leone except imported wheelchairs. The imported inappropriate wheelchairs distributed by some organisations break down in months or even weeks. Considering the definition of an appropriate wheelchair, imported wheelchairs don't meet any of the criteria.

The second presenter outlined the activities of the wheelchair technologist for HI in the national rehabilitation centre in Freetown, southern centre and outreach programmes. Two weeks of every month the outreach team of PO technician, mid-level therapist, Wheelchair Technologist and rehab worker visit disabled people in the community. HI staff support the activities including making various mobility aids including wooden crutches.

### South Africa 'Standardisation of Provision of Mobility Assistive Devices in South Africa' by Elsje Scheffler.

Feedback on the national policy created in 2003. Elsje outlined how the national policy recognises the way that assistive devices (ADs) improve the quality of life of people with disabilities. It recognises that all regions and institutions should have budgets for assistive devices and assessment must be carried out by professional therapists. The discharging institution should not alter the prescription, and high risk patients must be provided with the equipment they need. All assistive devices remain the property of the health system and have to be returned for recycling.

The policy was created in consultative process with many diverse stakeholders. Elsje highlighted that although South Africa may seem far ahead of other countries with the policy, it began with a few people starting something small in one province and it later expanded to a national policy. She encouraged others to begin the process in their countries.

**Uganda** Angela Balaba, Director of Spinal Injuries Association of Uganda presented on 'Legislation on Disability and Wheelchair Services'. Angela started by explaining how previous dictatorships had persecuted people with disabilities particularly the brutal regime of Idi Amin. Many smaller associations and organisations came together to form the National Union of Disabled People of Uganda (NUDIPU). She explained about the affirmative actions to ensure representation for all disabled people particularly at all levels of government. The SIA is one of several marginalised groups which are not full members of NUDIPU. While there are Ugandan government policies on Health, Education, Accessibility, Road Traffic and Disability, the practical implementation is limited because of many issues including access, prejudice, money, corruption, etc. The Disability Act was signed by the President in 2006. She called for wheelchairs to be nicely done. **Zimbabwe** Bigboy presented 'Country Legislation in Zimbabwe'. In Zimbabwe the Social Services Act says that the government should provide assistive devices, including wheelchairs. The reality is that there are many excuses used to deny people with disabilities the assistive devices. Standards for wheelchairs are yet to be discussed at a National policy level. Although the legislation is in place, the government is not compelled to implement them in real terms.

### Plenary Discussion

**Q:** Are we concluding that African governments have policies that are not being implemented?

**A:** In South Africa policies are used as a vehicle to achieve improvements – need commitment of service providers to stand up and fight and people with disabilities should be aware of the policies.

**Comment:** Wheelchair Builders Union in Uganda has office bearers in place. Activities are networking, lobbying government to take responsibility for wheelchair provision and to recognise the profession of wheelchair technologists.

**Request:** Is it possible to get the resources from the congress for future use?

A: All congress information will be available from the Secretariat on a CD.

**Q:** Is it possible to come up with a Pan African organisation to make sure every government is lobbied?

**A:** Perhaps the conference could ask Joe Obiedo to take that message back to WHO from this meeting – a request for WHO to promote the guidelines to governments.

**A:** We should support the existing structure rather than start new ones. It is up to the people and NGOs to push the government. WHO usually works with MOH, but sometimes other ministries are in charge of wheelchair provision.

**Comment:** Governments have so many things on their plate, unless DPOs are noisy and active, government will not do anything.

**Comment:** Disability is not supported by donors in the same way as other issues such as Malaria.

**Comment:** Lobby for procedures for forcing imported, donated wheelchairs to be incorporated into official systems of distribution.

**Comment:** Response to Angela in support of wheelchair technologists embracing the request that Angela made for better wheelchairs. Quality of materials is a big challenge that affects the quality of wheelchairs.

**Observation:** In relation to previous presenters speaking about recognition for wheelchair technologists – look to PAWBA to clarify role of wheelchair technologists and therapists. Feel that success will come if everyone pulls together and gets involved.

**Comment:** Cooperation with DPOs – building trust with professionals and users. Building quality control and standards – lobby for governments to monitor quality standards from DPO up to national level.

**Comment:** Wheelchair Technologists also must fight for their right to be recognised, raising awareness and joining international associations.

**Comment:** It's up to you to lobby governments. Governments have many urgent issues to respond to. WHO have only received 1 request from a MOH for support in the last four months – lobby your government MOHs to put proposals to WHO.

The participants then moved into four groups and the following were report back reports:

### CP Wheelchairs Group

The group agreed that the proper description be called; Postural Support Device'.

#### Two definable areas:

1. Adjustable, modular, fitted around a range of user needs. Seat must be a firm base, not a canvas or slung seat. Cushion needs to be in place and easily adaptable to client needs. Pelvic strap should be in every chair.

2. Include a tilt in space option. Optional arm support, adjustable footrest, active self-propel option, optional armrest support, and other standard features.

**Elsje:** Fine to have the product but you need training in how to use it or it can cause more harm than it does good. Therefore training has to be done jointly with the product.

**Hubert:** Suggests that one of the congress resolutions is that different levels of training are required and propose that standard designs be developed to help producers develop appropriate chairs.

#### Standard Wheelchairs

Ralf compared the different designs of wheelchairs, the long and short wheel base. Talked about how the longer wheel base makes it more unlikely the chair will tip over forward, but the short wheelbase tips forward more often. The 12% seat angle helps prevent tipping out forwards but still can be a problem.

Usability of each design in the house; the group tried some different chairs in different settings.

Ralf informed the participants that so far they have only made a 24" wheel model. There is a 20" long wheelbase version in trials in Colombia. Very

adjustable from 8.5" to 12" Seat depth – 9-11" range. In Nigaragua they made a version with 12" wheels.

One participant wanted to know if the size of the caster wheel had any bearing on the functionality of a wheelchair. Ralf pointed out that anything is a compromise. If the wheel base is short it's going to tip over – once you extend the wheelbase you don't need to worry about the size of the front wheels so much.

Spent last evening on a 9" front castor and that was nice to ride, but it will be tight to fit in small spaces and public transport.

Question: What about the issue of leaving some space either side of the seat?

Everest & Jennings introduced large and extra large to make it easy for themselves but there isn't a need for a big space either side. Make the chair fit the person.

**Jamie Noon**: Smaller castor you can deal with taller people. Larger castor you can't accommodate taller people. Adjustable axle position needed to tune the chair so you don't waste a lot of energy putting weight on the front.

**Kenny:** Appealing for information on the seat width. Certain books are giving different information on the seat width calculation. The concept of 50 each side was being used when the training started but when we discovered 50 was too wide we reduced to 30. In Zambia it was agreed that it should be 20.

**Ralf:** For the sake of the future trainees adopt a standard rule for the training of adding nothing. If the different size of wheelchairs go in 4cm increments, then the biggest gap will be 20 each side.

**Jamie**: Rather than saying zero is the starting point there might be an additional clinical consideration.

**Elsje**: Clinical consideration ties in with Ralf's statement 'add nothing' because we've found we've been able to provide better postural support by only rounding up to the next available size. So the rule should be 'add nothing'. People often lose weight then go back to their standard weight so we ask people to bring clothes they wore before.

Ralf: The loose skin should be taken into consideration when you measure too because it can be squeezed and it doesn't do any harm.

### Sports Wheelchairs

The group discussed different features of the chairs for use for basketball and looked at DISACARE's sports chair.

**Hubert** – Any recommendations – ie is there a demand for sports wheelchairs? Appeal to all the workshops to look into it seriously.

**Kenny** - 1996 – had an opportunity to go to Finland and we saw the wheelchairs there. Appeal to all workshops to introduce wheelchair sports chairs.

**Hubert** – should we have a recommendation on sports chairs from the congress.

**Isaac** – are we satisfied that DISACARE are doing enough or should other people be doing this? What is the difference between the different sports chairs?

**Matt** – Person in the Philippines making marathon racing chairs – nice thing about them is that a lot of people will see someone using a marathon racing chair.

**Ralf**: Size applies even more so for sports wheelchairs.

**Kenny** – DISACARE have the drawings for the sports chair and jigs but won't be able to release those to the congress as they want to come up with a training manual.

### **Tricycles**

2 trike users from Moshi were part of this group, and some of the conclusions were as follows:

- Pavement / smooth road front wheel drive is fine but in loose sand, rear wheel drive may be better.
- Long distances and carrying stuff ability to carry things very important.
- Because of its carrying capacity the trike can help in starting a business.
- Seat width is not such a big issue as peddling in front.
- Distance from seat to drive is very important. Climbing hills want gears, but also want low maintenance costs.
- Protection from sun and the rain another factor.
- Postural support for some people it's as important as in a wheelchair.

### **Comments**

**Peter Mbugua** – safety of the user – it's well taken care of because there are reflectors. Safety belt – many don't want to have a safety belt. Weight 30kg. Main frame bent out of one piece of pipe and that reduced production costs substantially.

**Hubert** – APDK has been producing trikes since 1994. Got a lot of feedback, and did research and had an expert who spent a year and tested 5 designs.

### Day Three: Wednesday 19<sup>th</sup> September

### Theme: Wheelchair technology training

### Jamie Noon – 'WHO / ISPO Standards for Wheelchair Products'

Jamie commented that the definition of an appropriate wheelchair, as defined by the WHO/ISPO Bangalore Wheelchair Consensus Conference (WCC), does not allow for an assessment and fitting but that it provides it. The consensus definition is a useful tool that should be used to influence countries' national approach and then to develop national standards on wheelchair services.

The implementation of the guidelines will lead to a variety of wheelchairs that are safe, affordable and long term in less resourced settings. The guidelines should cover both locally produced chairs and imported wheelchairs.

Jamie reiterated that no single wheelchair will meet all the needs of all wheelchair users. Supply methods will often have more of an impact on wheelchair standards than the standards themselves. The wheelchair consensus conference encouraged user involvement at many stages of design and production and testing.

**Ray Mines** – Motivation - commented that ISO1767 were put as a minimum in regards to testing. These standards are not only minimum in terms of standards but they are not very accessible, in part because they have to be paid for. A working group has been set up to establish a more accessible set of standards that will be published as an appendix to the WHO guidelines.

**Ralph Hotchkiss** – Whirlwind - Whirlwind developed test guidelines in 1995, which are easier to carry out than ISO standards.

**Piet de May** – There is need to have different standards for different types of chairs. Furthermore, each government should develop its own standards.

### Harold Shangali – WHO/ISPO Standards for Services and Training

ISPO has been involved with WHO in development of standards and is a member of the ISO. Mr Shangali outlined ISO 9999 which defines an assistive product.

He went on to outline the basic wheelchair recommendations for developing countries. It was requested that ISO revise their basic standards for specific areas of wheelchairs in developing countries through a sub committee. In general, standards should also exceed ISO standards, and be relevant to each country setting.

The debate on acquiring wheelchairs through imported channels or local channels has to be balanced by considering a variety of factors unique to each setting. He suggested that testing to ensure quality should be the starting point before the implementation of standards.

### TATCOT Training Centre

It was explained that TATCOT was established through a bilateral cooperation between Federal Republic of Germany and Republic of Tanzania in June 1981. TATCOT is run under the Ministry of Health in Tanzania. The structure was outlined which is divided between academic and management issues. An organisational chart of TATCOT was then explained.

The staff body (full time and part time) are both academic staff and supportive staff. The roles of each position were explained in terms of their profession and their category of training levels.

# Western Cape rehabilitation Centre (WCRC) Wheelchair and Seating Training - Elsje Scheffler

Elsje outlined South Africa's dual healthcare system with private and state welfare services. 80% of the population relies upon state healthcare support. Wheelchair services have been established at WCRC and the work of a provincial mobility assistive devices committee has been helpful. All staff involved in wheelchair services must be trained; they work with a reference handbook which is regularly upgraded and the training course is upgraded annually.

The training was developed in 1995 and has evolved from a half day workshop to a modular course of three five-day modules. Target groups are diverse including physiotherapists, Occupational Therapists, Nurses, Doctors, Speech Therapists. There are also secondary target groups such as NGOs, DPOs, workshop staff etc.

Module 1: Basic seating: covering the wide range of chairs available on government tender. They also cover ISO and local standards in this module. The principles and biomechanics of seating are also covered along with assessment, prescription and fitting. Product preparation and adaptation as well as product specific training is included. In addition to the clinical training, management issues and 'practical with patients' is included.

Module 2: Intermediate Level Training: covers similar topics but in view of more complex seating.

Module 3: Advanced Level Training: covers severe deformities, fixed deformities and those that cannot be seated.

Elsje outlined the wide teaching methods for these courses and then went into the future training planned for WCRC. Training opportunities are offered to other provinces, private sector, manufacturers and designers and NGOs.

### Plenery Discussion

**Gladys** – DPOs should be included as much as NGOs in the training opportunities because they are the end users of the products.

**Hubert** – Are you extending these opportunities to all over Africa?

Elsje – Yes, the courses are low-cost, but we cannot fund flights etc.

# DISACARE Regional Resource and Training Centre – presented by Casserdy Magaya

In addition to wheelchair production, DISACARE also offers training. Current training activities include wheelchair manufacturing and repairs. Future training plans are training in other mobility aids such as trikes, sports wheelchairs, crutches, business and short computer courses.

Main collaborators include TATCOT, FMD of Finland, Motivation and WWI.

People from six African countries have been trained in wheelchair manufacturing at DISACARE. The wheelchair repair training was introduced because DISACARE is the only wheelchair producer in Zambia, therefore it reduces costs if people in provincial areas are trained to carry out local repairs.

Trainees do practical and theoretical modules and make their own wheelchairs. After training follow up with graduates is carried out.

### Plenary Discussion

**Question** – Do you provide cushions for wheelchairs?

**Answer**– We do provide some cushions but we cannot provide them for all our wheelchairs, even though we would like to. We inform all our clients of the need for a cushion and their options for purchasing them.

**Question** – When you do follow up in different countries do you see that they are able to sell the wheelchairs that they are producing? Are they managing themselves or do they need further support?

**Answer** – During the outreach programme we look at the specific workshops and the management systems and procedures in the workshops.

**Question** – Do you work with people with CP?

**Answer** – Yes after we have identified we do the assessment together with CPI. We are partners with the organisation.

**Question** – After the training is your certificate recognised internationally or in Zambia?

**Answer** - Currently it is not recognised but in the long term we would like to professionalise the course so that it becomes a recognised qualification.

**Question** - The training is it long enough?

Answer - One month is not enough for technical and clinical; we plan to extend

Question - What about paying for the training?

**Answer** - Initially we thought trainees should pay something but this is not possible for the majority of trainees. Therefore costs have to be met by our funders.

# Wirlwind International (WWI) Training Programmes – presented by Ralph Hotchkiss

WWI is primarily involved in technical assistance. They have recently been working with DISACARE on developing trikes and basketball chairs. DISACARE has just finished one of WWI's training programmes.

The premise of the new design is: the user, the terrain, reliability and repair, low cost solution and activity.

WWI works through the following processes: identifying local partners, finding funding for support, 'setting up shop' and training for manufacture, fitting, sales/marketing, user training and follow up. WWI's approach is 'rider focused', and projects currently include making children's chairs. (Ralf showed the WWI video clip demonstrating their design advantages in comparison with other chairs).

WWI has experimented with building chairs in India and shipping them to Afghanistan where they have trained local people to assemble and fit the chairs. There are advantages to this process in terms of efficiency and when there are not locally available. The cost is sometimes cheaper, but not always.

### Motivation Training Programmes - Christine Cornick

Motivation covers both formal standardised training and informal training courses. Training is a dynamic field and the recognition of the need for professional services has helped spur forward the development of Motivation's training recently. Motivation's training needs are guided by WHO guidelines.

Fit for Life (FFL) prescription course; trainees have come from five countries. No previous qualifications are needed for the FFL course. It is a participatory active course that has been 'packaged' professionally. There are clinical and technical elements of the course that are compressed into three weeks of learning. The course objective is that trainees should be able to assemble, fit and instruct on maintenance of wheelchairs.

Wheelchair and Postural Support Training: This is an 8 day course developed in partnership with ICRC aimed at category one level prosthetists and qualified physiotherapists. Once this course has been delivered the trainees can deliver the FFL course to national staff.

Supportive Seating Course: 3 month course and modules are one month each. Trainees either cover technical or clinical side.

Referral network training: 2 day course teaching a basic understanding of wheelchair user needs so that they can be referred on appropriately.

Currently being developed are:

- 2-3 year modular course in wheelchair technology.
- Supportive seating training looking to develop products, services and training in supportive seating
- Short courses on assessment and prescription at TATCOT
- Formalising and standardising peer group training
- Wheelchair repair course, formalising existing training so that it can be packaged and delivered.

### Plenary Discussion

**Joe Obeido** – WHO - What about centralised manufacturing in Africa. Would this aid standardisation?

**Ralph Hotchkiss** – WWI - As long as the chairs are centrally built it would be hard for small shops to build them and it would also reduce competition which could raise costs.

# Wheelchair Project Massachusetts Institute of Technology (MIT) Student Presentations – presented by Amos Winter and Lindsey

MIT's role in developing mobility products for developing countries was outlined; these include free research by students, exchange programmes and bringing increased awareness about the issues experienced by wheelchair users worldwide.

The main issues that arose from an assessment trip to Tanzania in 2005 were the high cost for products and little local funding. It was found that 65% of disabled people crawled as their current form of mobility and that the average age of receiving their first mobility aid was 21 years old. It was also found that disabled people chose to use tricycles in Tanzania because they like/need to travel more than 5km/day. This is the best mobility aid for this type of movement.

Following the assessment trip, a manual that outlines engineering principles in a user friendly format was written. The manual aimed at outlining practical solutions to the problems local manufacturers encountered such as carrying out repairs.

The project development classes that are held at MIT were then elaborated on. They begin by defining the problem, then collaborating and developing ideas, then testing and implementing the design and finally distributing it.

Lindsey then elaborated on their current projects:

- 2 speed trike design
- Folding three-wheeler
- Improved tricycle frame design
- Marketing strategies for local workshops including brochure design, information pack for wheelchair users and how to create a free website

Class projects for 2008 include: increasing exposure of local workshops to foreign donors through a 'worldwide network' computer programme, educating donors about appropriate technology, examining ways that mobility aids can be used to generate income and folding modifications for existing designs. MIT is available to support workshops. If workshops are interested in having students attached to them they can get in touch with the institute.

### Plenary Discussion

**Joe Obeido** – WHO - What is the long term sustainability of this project? Will you be interested in working in West Africa? In your presentation you talk about finding one ideal mobility product, but it is more likely that in an ideal world people will want more than one product.

**Amos** – We are hoping to establish a unit of mobility products, I am there for the next few years and when I leave I will be replaced and the unit will continue so it is sustainable. We would be interested in working in West Africa. MIT does have the time and resources to look into one ideal solution – it may not be possible but it is something as students that we can look into.

**Christine Cornick** – Motivation - congratulated their presentation but said to be aware that a worldwide internet network could be abused and would need monitoring by a body like PAWBA. Christine also pointed out that some of the designs that Amos attributed to Europeans and Americans were in fact African designs carried out in collaboration with Europe and America. Christine also pointed out that trikes are more visible rather than necessarily more popular. They can be made more cheaply but a lot of people are unable to use trikes and therefore it should not be presumed that they are the preferred solution. Christine also mentioned that the 'ideal' all in one product could put off donors because of costs.

**Piet de May** – Angola MoH - Research is much needed – you should try to involve a university or a technical school locally as well.

Jamie Noon – Keep in mind the need for clinical input in your design processes.

### Peer Group Training (PGT): Different Country Experiences: Zimbabwe, Tanzania and Uganda – Gladys Charowa, Faustina Urasa and Angela Balaba

**Gladys** outlined the background to PGT. The main objectives of PGT are to educate, share ideas and information and to promote a sense of belonging and worth for wheelchair users. Research in Zimbabwe before PGT indicated that people with a SCI were dying within two years of their injury because health professionals were not aware of how to treat SCI and appropriate equipment was not available to people with a SCI (eg urinary equipment). Gladys also attributed the high death rate to inappropriate wheelchairs and false hope given by faith based organisations.

Gladys outlined the steps that have been taken to reduce SCI deaths in Zimbabwe, including a training manual on how to treat SCI that is being

distributed to health professionals, lobbying the government to provide urinary equipment and PGT at provincial and national hospitals. The impact of PGT has been evaluated by Zimbabwean Ministry of Health and Child Welfare which revealed that the government was saving 80% of its resources and that there was a drop in pressure sores. PGT also means that wheelchair users are more able to contribute to their families and to return to employment. Importantly, wheelchair users also become more aware of their rights.

**Faustina** outlined what PGT is: the transfer of skills from experienced and active people with a SCI to others with a SCI. It encourages people with a SCI to take a more active control of their lives – and peer to peer training is the best way to do this. The main issues that PGT covers are individual and group discussions on: health issues, emotional and psychological issues, accessibility, sexuality, techniques and skills for using supportive devices and following up of the participants of PGT. As a result of PGT people have improved health and live longer.

Home and hospital visits are an essential part of PGT. Getting to meet the patient in this setting enables the trainers to talk with the patients, encourage them and talk about practical issues such as how to make their homes accessible.

The main challenges facing PGT are mobilising resources and participants, especially with a lack of accessible transport. There is a need to develop resource materials and to train trainers in other areas. Awareness is key to addressing these challenges. The results of PGT to date are improved quality of life, changed attitudes and increased awareness.

**Angela** started by thanking and congratulating Christine Cornick for all her work with the four DPOs in Africa that have been working with Motivation.

An important part of PGT is peer counselling for the newly injured, through listening and giving self examples. Working with the family and community by educating them on SCI issues so that they understand what is involved in the rehabilitation of the wheelchair user.

To empower trainees they need to cover issues such as bladder and bowel management, sexuality and sex, coping with different terrains, physical barriers and mobility skills, transfers and how to maintain a wheelchair.

SCI rehabilitation involves doctors, physiotherapists, occupational therapists, nurses and the media. It is important that rehabilitation makes people aware of their rights – from marriage to employment to accessibility to structures and information. PGT can be used as a tool for lobbying, fundraising, to strategise with and to negotiate with.

### March to Moshi Town

Delegates spent the afternoon session marching to Moshi town to visit a variety of public buildings. Two groups were formed - one group visited a variety of accessible buildings and gave the managers a certificate acknowledging their accessibility and thanking them for recognising the needs of disabled people to have equal rights to access.

The second group visited a variety of inaccessible buildings to raise awareness of the importance of access for all and to request the institutions to recognise the rights of disabled people and to make their buildings accessible.

The group marched between venues with banners to ensure that the town residents were also given the message of the importance of accessibility.



Wheelchair users matching in Moshi Town to sensitize the community on accessibility right

### Day Four – Thursday 20<sup>th</sup> September

# Theme: Capacity building and managerial skills in wheelchair provision

### Wheelchair service presentations

#### Sudan

Fafa informed the participants that ABRAR, a local organization in Sudan, offers services for people with disabilities, landmine survivors and war affected communities. Projects and services include medical services, vocational training, referral, reintegration, micro-credit, socio-economic reintegration, human rights activities and a wheelchair workshop in South Khartoum.

### KCMC Tanzania

Albert Mushi started by presenting the background to the wheelchair service in Kilimanjaro. The wheelchair committee was started by interested professionals at KCMC in 1996, in order to provide and repair wheelchairs for people in great need. He showed some photographs of the wheelchair technicians at work in the workshop, assessing a client, etc. Albert went on to outline their system of wheelchair provision and follow-up, the skills training that they carry out, and repairs and maintenance.

### Workshop review experiences: TATCOT

TATCOT has a responsibility to follow up all of the WTTC graduates to assess if they are implementing what they have learnt in order to maintain quality. It was reported that in general wheelchair workshops had been started and the technologists were very committed to their profession.

The review revealed the following challenges; unavailability or high cost of bearings, castor wheels, chip foam, financial instability, etc. One challenge is that donors ask for the wheelchairs to be delivered without the technologist seeing the wheelchair user thus compromising the appropriateness of the wheelchair to the user. TATCOT is committed to further developing the course to incorporate the lessons learnt during the review process.

### Challenges of small scale workshops

### LOREWO Oshakati, Namibia

The presenter started by outlining the history, staff and main activities of LOREWO workshop including manufacturing and repairing wheelchairs. Products include wheelchairs for adults and children, cushions and other assistive devices, and the main donor is SINTEF of Norway.

Therapists or medical rehab workers carry out assessments and send the completed forms to the workshop. Transport is a challenge and this makes it difficult for follow up and field based assessment and prescription. To improve access to people the workshop is working closely with hospitals.

#### MADE, Uganda

Fatuma Acan started by explaining that MADE was started in 1999 by disabled women who wanted better wheelchairs than were available on the market. Original objectives were to produce wheelchairs, raise awareness and create job opportunities for women. The workshop has worked with a number of NGOs and individuals in making wheelchairs for disabled people. Fatuma observes that there is still a lot of prejudice against wheelchair users in Uganda.

# Wheelchair financing systems: three approaches: Tanzania / Uganda / Zimbabwe.

Andrew Kachingwe began by explaining that wheelchair users do not have very much purchasing power and lack choices because of decisions made by other people.

Gladys started explaining about the wheelchair financing committee established in 2005 in Zimbabwe to create a database of people in need of assistive devices, identify sources of devices, purchase them and distribute them. Achievements so far have been to form committee, Terms of Reference, development of means testing schedule, distribution of 50 Worldmade wheelchairs and receiving consignment of 360 new Worldmade wheelchairs and spare parts. Challenges include lack of funding, fuel shortages, voluntary commitment hard to secure, etc. Future plans include registering the Wheelchair Finance Committee and educating donors on how to make wheelchairs available.

David Kisombo from Uganda explained that the wheelchair finance committee (WFC) was established to develop and maintain a fund that enables people to access appropriate and affordable wheelchairs, to raise awareness of the fund, lobby government and monitor quality of production and distribution. The WFC is comprised of the following main stakeholders; MOH, COMBRA (Community based rehabilitation alliance) and ADD. Achievements of the WFC so far include establishing a Terms of Reference, receiving USD\$10,000 from ADD and assisting 30 people with wheelchairs. Challenges include low production, quality, government funding inadequate, demand is very high, and influx of imported chairs.

Andrew summarised by suggesting that PAWBA can work together with national organisations to use the guidelines and UN convention and lobby government to take wheelchair financing issues on board.

### **APDK – Empowering people with disabilities**

Hubert began by explaining APDK's vision and briefly outlined some facts and figures about APDK. They offer many services and a wide range of products. APDK's annual budget is US\$2.5m, of which half is from donors and the other raised from sale of assistive devices. Demand is high and waiting lists are still long. APDK has nine branches throughout the country with seven up-country branches which are integrated into government hospitals. Hubert went on to describe the activities and services at all of the APDK branches including micro-finance, wheelchair production, handicrafts, awareness raising, furniture making, CBR, physio and occupational therapy, mobile clinics and orthopaedic workshops.

### APDK Economies of scale: survival of the fittest – Hubert Seifert

Hubert started by defining 'economies of scale' as the saving in the cost of production due to the volume of production; decreasing overheads and fixed costs per unit, accessing lower input costs due to bulk purchases and investing in more efficient production processes (automation).

Hubert went on to explain the history of the APDK production. He presented projections of 2,000 mobility products in 2007 increasing to 5,500 by 2010 and 20,000 by 2015. Importation has reduced costs of bicycle parts by 40% and castor wheels by a high percentage as well.

Cost saving factors include holding larger stocks, negotiating discounts with suppliers and investment into larger production facility and more automated machinery. Other opportunities include sales of components to other producers. The benefits of larger volume production are efficiency, improved quality, wider product range, opportunity for research and testing, lower unit cost, able to compete with imports and able to attract donors. APDK are open to cooperating with other producers offering competitive prices, training, know-how, etc.

### Marketing practices – Peter Mbugua

Suggestions of strategies for effectively marketing products; market services and products as a whole package, identify business communities and seek their support (CSR budget, advertising budget, business partnerships for economic empowerment), approaching religious organisations (raising funds and awareness), charitable organisations (Rotary and Lions clubs), Medical and Social Institutions, Embassies and High Commissions. Major challenge is that we produce expensive products for people who are not economically empowered. For developing a long term relationship with donors it is important to develop good reporting systems.

### Standardising wheelchair costing – Andrew Kachingwe

Andrew suggested that the costing starts with the strategic decisions that the organisation makes. The costing must include all the costs involved in every aspect of the wheelchair production and distribution and costs related to other activities of the producing organisation must be excluded from the wheelchair costing so that the cost is an accurate representation of the actual costs and is not subsidizing other activities.

### **ICRC's approach to wheelchair provision – Francois Friedel**

Francois explained the background of the ICRC in Prosthetics & Orthotics and that wheelchairs are a relatively new issue for the ICRC (apart from Afghanistan). Francois went on to explain the distribution of responsibilities between the orthopaedic programmes and the special fund, the geographical distribution of programmes, a summary of all appliances provided, where wheelchairs were distributed in 2006, the ICRC's commitment to improving services. Francois explained that whilst the ICRC wants to offer better quality wheelchair services with a range of wheelchairs available, they are not intending to be involved in wheelchair production. He went on to explain the ICRC's strategies including implementing training courses for ICRC expatriate and national staff and accessing appropriate products either locally made or imported. In 2007/8 ICRC are collaborating with Motivation to train all of their expatriate physical rehabilitation staff in wheelchair provision and they will support partners in the provision of wheelchair services in Afghanistan, Angola, Cambodia, DPRK, Eritrea, Northern-Iraq and Pakistan.

### Field trials in South Africa – Shonaquip

Shona MacDonald outlined the field trials of the Worldmade 3 wheeler in South Africa over 2006/07. She explained that the programme involves training of therapists in skills to assess to and prescribe the chair. The wheelchair is accommodating a much wider range of wheelchair users than was original thought possible. Some government officials and some regions declined involvement in the trial in their province because of the extra work involved.

Faults have been identified and documented and the product has been reviewed and improved. Transport has been a big issue and Shonaquip continues to lobby for increased accessibility. The Worldmade backrest and seat have facilitated complex postural support to be made for some clients. Spare parts have been taken from within the research batch and many chairs are now incomplete and parts will need to be replaced. Shona then showed a short video comparing the Worldmade rough terrain wheelchair with a standard wheelchair and showing its superior performance on rough terrain.

### Wheelchair bearing considerations – Ralf Hotchkiss

Ralf started by outlining that he has been collecting wheelchair repair cost information for 30 years mostly in Nicaragua (although he feels prices are similar to Africa). He circulated two charts and went on to explain how they itemized repair costs over 5 years. Ralf explained the forces on bearings in the castor wheel and castor barrel assembly and the range of available bearings and their failure forces. Ralf presented a bicycle bottom bracket bearing system which he has been testing for over a year on one side of his own wheelchair which is very cheap to purchase and maintain. He is hopeful that it proves to be strong, resistant to damage by dirt and extremely cheap to purchase and repair.

### Practical study on wheelchair accessibility in Moshi town

The presenter introduced the work which was a collaborative study with the YWCA. The aim was to raise awareness about accessibility, determine needs of people with disabilities and identify factors involved. The presenters showed several photographs of inaccessible buildings in Moshi. Outcomes included the fact that all service providers who were approached agreed to discuss issues, municipal architect was aware of issues and was open to discussing accessibility, one bank which was renovating their building included a ramp, one hotel was also willing to change their facilities and add ramps. Challenges include the attitude that adaptations are too costly, old

buildings difficult to adapt and some providers couldn't understand the need for accessibility. The campaign will continue so as to improve access in the town.

# ISPO assessment of wheelchair provision in Tanzania – Tone Oderud - Sintef

Tone presented the study carried out in Kilimanjaro area in 2006. Interviews were carried out with 47 wheelchair users, 27 of whom are KASI members. She explained the distribution of age, gender and onset of disability as well as other statistics were gathered.

Tone showed photographs of several wheelchair users in different types of wheelchairs and tricycles. The conclusions included that the different styles of wheelchairs have advantages and disadvantages, that trained personnel should be involved, product choice is important, local repair and structures are necessary to facilitate assessment and prescription.

# Comparison of wheelchair designs in the Philippines – Matt McCambridge – Handicap International

Matt explained the background of the HI trial of ten wheelchairs in the Philippines. He then showed some video of wheelchair users getting into various methods of public transport with a folding wheelchair and a Worldmade 3 wheeler. The next videos showed access to bathrooms, rough terrain, access in a market, narrow alleyways and use in the street. The full report of the findings will be published by HI in a couple months.

### Workshops

The afternoon session was given to a range of different workshops as follows:

- 1. Postural seating Nicky Seymour Motivation & Aston Ndosi TATCOT
- 2. Cushion design Jamie Noon Independent
- 3. Central sourcing and distribution Hubert Seifert APDK
- 4. 'World made' assembly Ray Mines Motivation
- 5. Fundraising and proposal writing Christine Cornick Motivation
- 6. Wheelchair mobility skills Abdulah Munish KCMC
- 7. Tour of TATCOT TATCOT

At the end of the day each group gave feedback and summarised the main information communicated through the workshops. All sessions were considered to be highly valuable and informative.

### DAY 5 – Friday 21 September

### Theme: Collaboration for impact

### Wheelchair Testing- Rodney Outram – CE Mobility – South Africa

Mr Outram emphasized the importance of testing and producing wheelchairs to set standards so as to ensure safety to the user and marketability of the product. There is a need to ensure that research and development continues so that product quality and affordability is addressed. He went on to point out the need for quality control during production so that standards are not compromised.

He noted that in developed countries there are some minimum legal requirements to be considered in wheelchair production and hoped that developing countries would speedily adopt some policies and laws that would provide guidance to wheelchair production and services.

A South African working group was set up to improve quality of SA chairs. ISO standards were used as a basis however quickly identified as not stringent and rigorous enough for the South African environment. The working group then focused on enhancing the ISO tests so that they can respond to the SA needs for wheelchairs

### Wheelchair Testing – Ralf Hotchkiss

Mr Hotchkiss observed that chairs that have passed the ISO tests are not durable in many low-income environments eg regular breaking of castor wheel forks.

ISO standards are appropriate for recreational chairs, but inadequate for the load weighting required in rougher environments. The Bangalore consensus conference is being used as a platform to start discussing the required enhancement to ISO standards.

Examples of testing required include: component test, environmental tests, fatigue tests, functional performance tests and postural support tests. It is possible to create own testing methods if standardised testing equipment is not available: compare different materials according to the current standards and knowledge of requirements using innovative and creative ideas with locally available devices eg fish scales used to assess the strength of different thickness steel rods.

### Quality Control Procedures: Joachim Moshy – TATCOT

Quality control is the procedure carried out to maintain high standards of product and services. Wheelchair provision services need quality of production and services to ensure an appropriate product to the user. Joachim presented a video which showed good and bad examples of different aspects of production including cutting, welding, cleaning, and spraying.

### Economic Empowerment of Wheelchair Users - Hubert Seifert

Mr Seifert stated that the International Labour Organisation (ILO) conference recommendations state that member states should promote the involvement of Persons With Disabilities into employment, education and vocational training. Programmes for empowerment should be mainstreamed to ensure integration and equality.

APDK activities regarding economic empowerment include loans and grants to disabled people and in the majority of cases disabled people have managed to repay the loans. Donors are shown the real situation of an individual with a disability and encouraged to make donations to meet their needs and to facilitate the establishment of income generation projects eg rebuilding of appropriate accommodation for clients that have adequate space to rent out rooms leading to an opportunity for income generation.

The future plan is to develop an Employment Bureau for person's with disabilities as policies regarding employment are often not implemented.

### Donors and funding strategies - Hubert Seifert

APDK has in the past used different strategies to approach donors and has maintained relations with several of its funding partners. Due to improving capacity within APDK many funders have also been increasing their support for the organization. USAID is one such donor.

Plans for future use of funding include creating a showroom, micro finance projects, establishing a supportive seating service.

Latter day Saints (LDS) - A recent agreement with LDS has been finalised consisting of the donation of funds equivalent to 100 wheelchairs per month instead of imported wheelchairs.

Rotary and Lion Clubs - They are starting to quote the Bangalore guidelines and the need for an appropriate wheelchair.

Safaricom – Many funding opportunities in Kenya currently being realised and potential for similar activities in other regions should be explored.

World vision – working on partnership for service development.

Long term strategy - full integration of services into government health budget because it is not possible to develop quality rehabilitation services without working with government. Proposals need to be directed through governments - independent funding is becoming more difficult to access and the benefits of being part of a national government strategy was emphasised.

#### DWSO – Economic empowerment in Zimbabwe.

DWSO focuses on small businesses, the majority being in rural areas. The organization is also lobbying government for effective vocational training programmes leading to employment, though such training does not necessarily lead to employment.

#### Henry Nyamubi- KASI -Economic Empowerment for wheelchair users

Being provided with a wheelchair is like opening Pandoras box for a person with a disability. It creates the desire for one to support themselves and their families.

People with disabilities often have a low level of skills and education. SCI often leads to an end to opportunity for education and employment. Vocational skills training programmes are not inclusive and the stigma associated with disability works against opportunities to employing and training disabled people.

### Gladys Charowa- Planning for a National stakeholders' conference

Zimbabwe held a Conference in September 2006 for all stakeholders who had interests in the manufacture or distribution of wheelchairs. The main challenge was the mobilization of resources and most donors still do not see the importance of a wheelchair to a user. However the congress gave the opportunity for stakeholders to share experiences and to nominate a task force made up of different stakeholders who could move relevant issues forward.

### PAWBA General Meeting

**David Mukwasa – Chairman of PAWBA.** David was invited to welcome delegates to the first General Meeting of the Pan African Wheelchair Builders Association (PAWBA). He introduced the acting office bearers as follows:

David Mukwasa - Chairman Yona Ezekiel – Secretary Hubert Seifert - Treasurer Joackim Kessy – Coordinator Davis Sharima – Administrator

He acknowledged the support that PAWBA has received from TATCOT who offered to house the secretariat.

He pointed out that since the last congress the Executive Committee and the staff worked on the constitution and the registration of the organization in Tanzania, and fund raising for the 4<sup>th</sup> Annual wheelchair congress which had been very challenging hence the postponement of the congress from 2006 to 2007.

He said the main future direction of PAWBA is to:

- Build the capacity of PAWBA.
- Encourage implementation of the WHO wheelchair guidelines
- Supporting and promoting regional production good methods to improve quality of products and standardisation of components.
- Lobbying African governments to adopt policies and approaches that improve the wheelchair services.

### **Treasurer - Hubert Seifert**

Mr Seifert informed the participants that the first 2 years were very slow due to limited funding until a grant from Motivation initiated some activities and he presented a summary of the expenditure from August 2006 to July 2007.

#### Yona- Secretary PAWBA

Mr Yona bemoaned the delays in formalizing the membership of PAWBA and requested members to speedily address the issue so that the organization can establish a register of members. 'Having a roof without walls does not make a strong building'. He strongly encouraged delegates to become members of PAWBA to facilitate it becoming a stronger and more effective organisation. He encouraged the creation of National associations to work with PAWBA and recommended a fee of US \$50 per year.

### Resolutions

Isaac Nyathi was requested to present some of the resolutions that had emerged during the discussions to be discussed. The following were the resolutions that were outlined:

- PAWBA to ensure that affiliated workshops distribute wheelchairs as provided in the WHO guidelines.
- PAWBA to lobby governments to adopt minimum wheelchair standards.
- To encourage regional production where it brings in economies of scale.
- PAWBA to engage with other Pan African initiatives or groupings like ARI, the Africa Decade Secretariat, Africa Development Bank, COMESA and other economic and political groupings to bring issues of wheelchair services to the African agenda.
- Wheelchair Services to work in collaboration with DPOs and be sensitive to the unique needs of the users.
- PAWBA to ensure equal opportunity in participation in its structures.
- To seek affiliation to internationally recognised associations.
- To lobby governments to recognise the Wheelchair Technologist Certificate course.
- PAWBA to explore possibilities of centralised purchasing.
- To support research and development to improve product quality.
- TATCOT be asked to speed up the process of upgrading the certificate course to a diploma.
- The name of the organisation be changed from Pan African Wheelchair Builders Association (PAWBA) to Pan African Wheelchair Association.
- WWI and Motivation be co-opted into the Executive Committee of PAWA to strengthen the work of the organisation.
- That standard designs be developed to help producers develop appropriate chairs.

### Plenary Discussion

**Piet De May** - Recommended that when fundraising for individual wheelchairs the price of maintenance for up to 5 years should be included because this is the real cost.

**AK Dube** - Suggested considerations to take into account when moving PAWBA forward:

- Research and development programme
- Centralised production strategy and regional strategies
- Peer group training
- Marketing and advocacy
- Capacity building of in-country facilities and wheelchair producers
- Policy and legislation

**Christine Cornick** commented that PAWBA should support the development of a hierarchy of training to deliver services at all levels and that advocacy work should be carried out on organisations such as the WHO and ISPO who may be able to support activities related to wheelchair training.

**Ezekiel Isanda -** KPO Kenya – Commented that PAWBA should take the lead in ensuring standardised wheelchair production in terms of quality as well as the choice of adequate products to prescribe from.

**Hubert Seifert** – Recommended change of name of PAWBA to be more inclusive of DPOs, therapists and other stakeholders.

**Nancy (Kenya)** – Recommends a mechanism to ensure quality of all wheelchairs produced in Africa.

**Shona McDonald** – Emphasised that without training and effective clinical services, even the highest quality of wheelchairs will not suit the users' needs adequately.

It was said that membership forms should be readily available to allow others not attending this congress to become members of PAWA.

**John** - APDK – Raising awareness on disability issues, particularly access, is very important at each PAWA congress and should be included in all future congresses because the walk around Moshi was very effective.

**Francois** ICRC- Supports the change of the name to be more inclusive and encourage more therapy services to become involved.

**Jamie Noon** - Supports the name change – limited resistance anticipated from wheelchair builders. Special interest groups can be represented under sub groups of the PAWBA umbrella.

**Yona Ezekiel** – Changing the name will result in loss of recognition and a need to start building again from scratch. The PAWBA constitution states that anyone can be involved including rehabilitation services.

**AK Dube** - No objection to name change as an organisation's name needs to reflect what it does. However, the constitution states that 3 months is required and then a general assembly meeting to institute a name change. We must follow the constitution rules.

**Adolphus Okeke** – We are currently creating identity among the outside world – once we have consolidated this identity then we can think of changing PAWBA's name.

**Tone Øderud** – An inclusive name will attract more interest as well as attracting more donations.

**Christine Cornick** – supports name change. PAWBA has started to become well recognised but it is not too late for a new name to be implemented; if the name were to change, now is the time to do it. This congress is going to lead to increased activities around wheelchairs. Specialist groups can be part of the overriding organisation.

**Shona** – A new organisation is being established in South Africa called WUFSA which stands for 'Wheelchair Users Forum of South Africa'. This brings all those interested in this issue together and assists in finding funding.

**Ray Mines** – Clarification is needed on what do members of PAWBA receive for their membership fee.

**Jamie Noon** - Supports Hubert's comments and supports Shona's comment regarding the need for standards related to service provision as well.

There was considerable discussion on the changing of the name and a vote was eventually held which gave the result that the 'B' should be removed from PAWBA to make it PAWA: *Pan African Wheelchair Association.* 

It was commented that the committee representation needed to be more balanced in terms of gender and if possible geographical spread.

#### **Elections:**

A proposal to return the Executive Committee in Block was supported and carried by the participants.

Nominations were taken for new committee members as follows:

Fatuma Acun was nominated to represent women and wheelchair technologists. She accepted the position of Vice Chairman.

Henry Nyamubi of KASI was nominated to join the committee to represent DPOs.

Motivation and WWI also agreed to be represented on the committee. Apart from the new committee members, the other committee positions remain the same for the time being.

#### **Congress Evaluation**

Delegates were provided with congress evaluation forms.

#### **Closing of the Congress**

The congress was officially closed and participants were thanked for their hard work and contributions during the week.

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ABRAR-Project Manage				0122233109		afafmaki@yahoo.com
· •						
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W/Chair Techologist	95	Blantyre	2659279436			jijijsiah@yahoo.co.uk
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					211200323	
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	2590	Windroel	061 2032796	0812560805	061245155	lorewo@iway.na
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			510-547-2704		413-330-1203	
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