



Report on Wheelchair Roundtable

Introduction:

The first National Wheelchair Services Roundtable was hosted by Uhambo Foundation in Cape Town on **17 October 2014**. A committee was set up by Uhambo Foundation in order to plan the event, identify and communicate with potential participants, host delegates, collate and distribute feedback for future planning. This was a full day event.

Uhambo Foundation's connection to wheelchair services

Uhambo means "to journey forward" in the Shona language. The Uhambo Foundation was founded in 2010 in recognition that there was a need for a non-profit organisation to address both national and international disability policy issues in South Africa. The Foundation operates as a registered Section 21 Company and Public Benefits Organisation in collaboration with Shonaquip (Pty) Ltd using the innovative Social Enterprise model recognised internationally as the ideal vehicle to promote sustainable advocacy, support services and capacity development to impact positively in the lives of people with disabilities. Historically, in South Africa, this synergistic approach was not commonplace, but in order to ensure success one needs to ensure financial viability of an organisation in an environment where total dependency on sponsors for programmes becomes a risk to the sustainability of any organisation. The Uhambo Foundation and Shonaquip recognised this and in an effort to show that an NGO and a business enterprise can ethically operate in partnership the social enterprise model was adopted and is gaining popularity within the social and entrepreneurship context of South Africa.

The staff of the two organisations cooperate to achieve the Uhambo Foundation's objectives with all funding received managed within the Uhambo Foundation's operational sphere. Shonaquip provides support and assists with design and development of products offered by the Foundation and profits produced through the collaboration are reinvested into the work of the Foundation. Shona McDonald, the founder of Shonaquip, has transferred 25.4% of Shonaquip's shares to Uhambo to ensure that the company and its staff remain true to its purpose and social vision.

The Uhambo Foundation, in identifying the need to address ongoing challenges in the sphere of wheelchair provision and wheelchair user support has therefore hosted the first Wheelchair Roundtable conference in Cape Town and we thank the National Departments of Social Development and Health for their support and endorsement of the conference.

Background to the hosting of the National Services Roundtable:-

There is broad agreement that wheelchair services has evolved rapidly during the past 2 decades in South Africa, supported by both international and national policy development. While implementation has become aligned with recommended policy, ongoing gaps and challenges in service provision impact on both users and service providers alike.

During 2008 stakeholders in the wheelchair service industry including users, caregivers, service providers and suppliers began meeting under the banner of WUFSA, a forum intended to provide an interactive forum for stakeholders. Unfortunately despite the provision of this forum, it could

not be sustained and the welcomed opportunity for broad based interaction of stakeholders around areas of common interest was lost.

The concept driving the Roundtable stemmed from this initiative, aiming to revive such a forum for networking, collaboration and action planning of stakeholders, with the optimism that should it prove meaningful to participants, it might become a regular event on the calendar of wheelchair service stakeholders and provide a united voice for people providing /affected by wheelchair services.

The purpose of the National Services Roundtable:-

1. To provide/facilitate an **interactive forum for stakeholders** to come together to share information and experience around areas of common interest in service provision, seating, mobility and support services.
2. To **stimulate discussion** around ongoing **concerns about services** and **training** related to wheelchairs/ users and **suggestions** to improve services
3. To use this opportunity to encourage both **networking and collaboration between stakeholders**, raising issues that could contribute to informing decision-makers in the future.
4. To **report findings and feedback** regionally from the Roundtable at the AfriNEAD conference initially and later, as decided by participants following the outcome of the event.

AfriNEAD : The Faculty of Social Science of the University of Malawi in Collaboration with the Ministry of Disability and Elderly Affairs, the Federation of Disability Organisations in Malawi (FEDOMA) and the Secretariat of the African Network for Evidence-to-Action on Disability (AfriNEAD) at Stellenbosch University in South Africa have gone into a partnership and are collaborating in the hosting of the 2014 AfriNEAD Symposium which will take place from 3rd-5th November 2014 at Sun and Sand Holiday Resort in lakeshore district of Mangochi in Southern Malawi.

Support from Governmental Departments

Endorsement of this event was sought from both the Department of Health (DoH) and the Department of Social Development (DSD).

A letter of endorsement was received from Ms MP Matsoso (Director-General: Health) dated 12/07/2014:

Extract: "As a key stakeholder in the field, the Department feels honoured to be invited to participate and also share our plans and strategies in providing wheelchairs to the indigent population. On behalf of the Department of Health I wish you the best of luck on this wonderful initiative."

A letter of endorsement was received from the Director- General of Social Development on 29/08/2014.

Extract: "As a Department, we are strategically positioned to share and contribute on mechanisms ensuring the social inclusion of children with disabilities, an aspect which will surely add value to the deliberation at the conference. We greatly feel honoured to have been invited to participate at your planned conference and wish you well in that endeavour."



Funding of the National Roundtable

An active decision was made by the planning committee not to use this planned interactive platform as a means to exhibit wheelchairs, so as not to distract from the focus on wheelchair services (not devices). As a result no funding was derived from suppliers in the usual way.

This did increase the challenge of fundraising especially within a 4-5 month time framework, decided upon so as to be able to generate input into AfriNEAD conference November 2014.

Despite dedicated efforts to seek funding for the event, it was not possible to raise sufficient funding to support participant travel /attendance from beyond the Western Cape. Funding as would have ensured more adequate support to the attendance of delegates from beyond Cape Town. John Du Preez did approach the following potential funders including ACSA; Telkom; ABSA; DoH; DSD (no budget); Eskom; Momentum; Allergan; Strandfoam and SABS. Responses were disappointing although there was some interest expressed from ACSA in sponsoring a possible similar event in the future.

Ernst & Young kindly sponsored the venue and provided on- site support in terms of dedicated parking for people with disabilities; audio-visual equipment, the use of on-site catering facilities, clean-up staff and permitted flexibility in terms of displays and layout in the venue.

Smaller but valued sponsorship of platters, wine, biscuits and muffins, beverages, participant hand-outs/pens/pads was given



Art Display: Tyler Washington kindly agreed to bring some impressive artworks or display in the foyer at Ernst & Young during the roundtable.

The Orion Enabling Art Centre (EAC) was launched in 2010 after realising the amazing talent our children and profoundly disabled adults have. In the past their artwork were utilised to give to donors as gifts, auctioned at events to raise additional funds, etc. However during a visit to the United States in October 2010, much appreciation was shown for the specific model and its great potential. The EAC aims to enable and liberate profoundly disabled artists to use their creative ideas and talents to elevate them from limitations to possibilities, by breaking down stigmatization, victimization and segregation. The objective is to use the EAC initiative to create opportunities to stimulate social dialogue and intervention, and inspiring social justice. The Orion EAC will be used as a catalyst and omnipresent symbol to bring about social justice, via addressing sensitive social issues, resulting in positive social change. Reference: <http://www.orion-friendship.org/enabling-art-centre.php>

Marketing of the National Roundtable

Marketing was done by Uhambo Foundation via a number of formal and informal channels for at least 4-6 months prior to the National Services Roundtable event. This was supported via a conference website (<http://wheelchairwordpress.com>) and included a Facebook page/Twitter handle. Direct contact was initiated through the Western Cape Forum on Disability, wheelchair service providers, community workers and suppliers across the country. Uhambo Foundation informed its broad range of networks nationally with NGOs, professional associations, schools and centres offering services or in regular contact with wheelchair users. Invitations were sent to a number of key decision makers around wheelchair services within the Dept. of Health, Dept. of Social Development and the Department of Education.

A database of directors of local care centres was also created by Uhambo Foundation in order to invite caregiver participation. Wheelchair users were invited via contact with Disability organizations or previous links through service to both Uhambo Foundation and Shonaquip.

Flyers were distributed at the RUDASA (rural doctors association, including rehabilitation therapists) conference in Worcester Western Cape (Sept 2014) as well as at the Neuro developmental Therapy conference wheelchair workshops (August 2014)

It was hoped that representatives would attend from provinces across the country, from both urban, peri urban and rural environments. However, with no dedicated funding forthcoming, it was not possible to fund sufficient participants' travel or accommodation costs. A few sponsored tickets were issued.

Attendees were invited to bring along any services promotional material from their organizations for participants.

Attending Participants:

A number of sponsored ticket holders did not arrive on the day, reason is not known (? Availability of transport)

Total number of participants attending on the day: 84

Government departments represented:

Department of Health: Maluta Tshivase (Director Rehab Services)

Department of Social Development: Manthipi Molamu, (Department of Social

Development's Director responsible for policy, strategies and programmes on disability)

Wheelchair Conference Participants

Professional Roles							
Physiotherapists	14	Dept. Social Development	1	Otto Boch	1	EC	3
Occupational Therapists	20	Dept. Health	1	Travel with Rene	1	GP	4
Seating Practitioner (non-therapist)	7	OPD-SA	2	Chairman	1	NW	1
Social workers	4	NACCW	1	Motivation	2	WC	59
Disability Co-ordinators / Consultants	5	Chaeli Campaign	2	New Era Transport	4	KZN	2
Social Development Co-ordinator	1	Rachel Swart Fund	1	Presta	1	International	3
Private Sector	6	Senecio	1	Jayson Chin & Assoc	1		
Fundraiser	1	NCPPDSA	1	Dare Consult	1		
Doctors	2	CTAPD	2	Shonaquip	6		
Orthotist	1	PACSEN	1				
Researcher	1	Reabled	1				
Nurse	1	Hospitals					
CEO/ Manager / Board Member	7	- Ditsolbotla Subdistrict	1				
Community Care Worker	3	- Khayelitsha Hosp	2				
Care-giver	4	- Groote Schuur	2				
		- Tygerberg Hosp.	2				
Wheelchair users	7	- Bergriver	1				
		- Red Cross Children's Hospital	1				
		- WCRC	2				

		- Sarah Fox Hospital	1				
		- Mseleni	1				
		Special Schools	6				
		Care Centres	4				
		UNICEF	1				
		Uhambo Foundation	8				
		Universities:					
		- UCT	2				
		- UKZN	2				
		- Stellenbosch	1				
		- Washington	1				



Invited Speakers: The following people were invited to address participants. They were chosen to represent the perspectives of a range of stakeholders, to provide some input to increase awareness around current issues as a foundation for discussions later. Speakers were drawn from the following provinces: Western Cape; Gauteng; Eastern Cape, KwaZulu Natal. They

included:-

- **Manthipi Molamu:** representing the Department of Social Development, and a wheelchair user herself, Manthipi is a strong advocate for appropriate wheelchair service provision, seating and mobility support services which are critical to ensure the participation and social inclusion of children with mobility impairments
 - **Elsje Scheffler** (key note address): Long history of involvement in development of wheelchair services nationally and internationally and training (Dept. of Health and World Health Organization).
 - **Sunette Wessels:** Mseleni northern Kwa Zulu Natal; experienced wheelchair service practitioner providing a lens on rural service provision
 - **Jacques Lloyd:** wheelchair user and experienced peer group trainer
 - **June McIntyre:** educator/academic at University KwaZulu Natal; wife of wheelchair user, experienced practitioner in seating service delivery and training
 - **Ruth Stubbs:** background in teaching of children with disabilities, passionate about promoting inclusion in schools and early intervention through assistive equipment, wheelchair service practitioner for Shonaquip based in Centurion (branch) and working in Limpopo, Mpumalanga and Gauteng
 - **Nolitha Vena:** a long time child and youth care worker with the NACCW. Throughout the many years she has been with Isibindi, she has held the position of disability facilitator, site mentor, and disability trainer and is currently a mentor supervisor for the Eastern Cape.
- Ari Seirlis (KZN):** wheelchair user/ Head of QuadPara Association (initially accepted an invitation to speak but withdrew 2 days before the event due to unforeseen personal

circumstances). He had planned to address the group on work done regarding wheelchair standards in SA.

During the planning of the Roundtable, the committee settled on **four basic themes** to help to direct speaker inputs and discussions for the day (but not intended to be exclusive of relevant issues arising from participants):-

- The gap between policy and wheelchair service provision
- Training across all levels of wheelchair provision
- Rights of wheelchair users and access to services
- The role of appropriate seating, mobility devices and services in early childhood development

Program for National Services Roundtable

The Director of Uhambo Foundation welcomed participants, followed by input from Manthipi Molamu from Dept. Social Development to set the collaborative, interactive tone for the day.

This was followed by a keynote address by Elsje Scheffler to reflect on the current state of service provision challenges in the country based on findings from recent research conducted in the Northern Cape.

Other speakers raised a variety of issues from peer group training to ethical practice and early intervention. Speaker inputs were interspersed with opportunities for questions from the floor, a structured small group discussion around training. The last session used the technique of 'open space technology' to identify topics of specific interest for participants, to allow opportunity for self-organization in attempting to address these topics. During this session participants were encouraged to contribute in their field of interest/concern and brief feedback was shared in the larger group. A wrap up session to be facilitated by Mansur Cloete (Director Uhambo Foundation Board) was planned following the open space discussion.

Session 1



Lorraine Frost welcomed participants and introduced them briefly to the work of Uhambo Foundation, to the plans for the day and the themes informing the conference program.

Manthipi Molamu, herself a wheelchair user, described as both activist and policy maker, opened the proceedings, affirming her commitment to children with disabilities, and reminding participants of the Department of Social Development's role as sole custodian of the child with a disability. She called for us to move beyond policy development, reminding participants that we need to focus on implementation of policy, on access to services in under resourced areas rural areas. Manthipi urged participants to invest in the children, enabling in such a way that they become fully integrated in the community through access to devices, support and services. Manthipi was inspirational in highlighting the importance of providing not just any wheelchair, but

an APPROPRIATE wheelchair so that the child with a disability can indeed prosper and become a productive and prosperous adult. She reminded us that we should not be seeing (without questioning) a child carried by a mother at the taxi rank, with legs protruding past the mother's body – why is the mother carrying the child, why has the child not got a wheelchair? Where have we failed this child?

Manthipi urged us *“to deliberate together, to share experiences but not to talk past each other”*. She commended all the known small activities in small corners across the country that were making a difference in the community, and encouraged participants to think about how best we could use our thoughts and experiences to deliver strategies that replicate good practice. Manthipi urged participants to *“Be visible, let us know who you are so that we can join hands”*. *Hold hands, share ideas and knowledge about what is needed – the time is now to deliver services”*. Manthipi urged participants *“to take up your responsibility, to share your thoughts and experiences which can guide strategies, unleash potential and replicate some of the provision of both proper devices and good services that do exist”*.

Manthipi shared the Dept.'s focus for 2014/15 on early childhood development, respite care, the training of caregivers and research focused on implementation with appropriate costing of services for people with disabilities.

Elsje Scheffler Physiotherapist Keynote Address

Elsje began her session with a short video clip from the WHO basic training package (The Story of Si) illustrating meaningfully the impact of sound training on a wheelchair user, in this case, using her appropriate wheelchair to *“take her books and attend school, play with others and build her confidence to make new friends”*. In this way, Elsje reminded us of the ultimate purpose of appropriate seating and services, i.e. to better the quality of life of the user and to enable them to access life opportunities of work, education, recreation and socialisation. Else briefly outlined local and international guiding documents and policies foundational to seating service provision. Implementing these policies requires dedicated rehabilitation and training to spread information to the user and to ensure the provision of quality mobility devices.

Participants were informed that the National Guidelines on the Provision of Assistive devices (2003) fell short of guidelines for all service steps and that there were limitations in both clinical focus and standards setting, dealing more with systems and bureaucracy.

Elsje presented findings from a qualitative research study conducted at 4 sites in the Northern Cape (Fraserburg district, 3 people per 1km) a region of high unemployment rate and an area which illustrates well what happens when policies are not implemented. In this area users travel 800 km to receive wheelchair services at Kimberley.

With a sample of 23 people (including users, providers and key community informants e.g. local APD, church) and using the wheelchair service delivery steps as a framework to describe and understand challenges, the following issues were uncovered in service steps delivery and program management:-

Service delivery steps: Else emphasized that service providers don't have to deliver each of these steps themselves, but you do know where to refer users to access the entire services

- Referral and appointment: focus was on users with better prognosis to the detriment of children with intellectual disabilities and the elderly

- Assessment: Lacked depth – needs significant training
- Prescription: often prescribed only 1 of 2 types of wheelchairs: buggies/basic folding frame wheelchair. Limited user consultation and excluding user from prescription choice. The inappropriateness of the basic folding frame wheelchair was highlighted especially in relation to the demands of the environment – gravel paths. **The folding frame is not intended for permanent or outdoor use**
- Funding and ordering: Handled by 3rd party in Kimberley 800 km from the user. Delays of up to 4 years. This has led to the situation in which the market is open to donor chairs with all their problems in terms of inappropriateness
- Product preparation: while the most basic of adjustments are done (e.g. footplate height), proper fitting is short-changed as is customisation of the wheelchair according to need
- User training: very limited and paraplegics lack understanding of health risks (e.g. pressure risks when adjusting footplate heights)
- Follow-up: Not happening, most important with children who require review every 3-4 months
- Maintenance and repairs: Done in Kimberley, far from site of use, and no loan wheelchairs available. Folding frame chairs prescribed inappropriately, suffer severe durability issues/have short lifespan

Program management by department

- In terms of management, there is a lack of human rights approach, services happen ad hoc, there is poor compliance, no outputs/outcomes and undergraduate training is exacerbated by limited mentoring and staff being limited by internal policies.
- Budgets are not ring-fenced, no planning with NGO re service delivery

Elsje encouraged participants that in some places things were indeed happening. She outlined positives and how we **can change going forward** through

- ✓ Infrastructure development
- ✓ Develop services at community level
- ✓ Use our existing rehab staff
- ✓ Utilise the enthusiastic staff we have who are eager to learn
- ✓ Use our international and national policies to drive services
- ✓ Ensure our available wheelchairs are appropriately used

In conclusion, Elsje urged the implementation of proper programs with all service delivery steps efficient management and clear outcomes and guidelines for service structure.

She voiced the need for trial wheelchairs, for PHC staff to be trained to identify and refer user; to develop repair and maintenance strategies, ensure proper consumables and tools, basic 5 day training and mentoring, wise use of donor chairs, appropriate wait lists with a budget to support the device (huge differences between folding frame and e.g. Posture support chair)

*She reminded participants with another WHO training video clip that **“when you have an appropriate chair, you forget about your disability”***

Reference to this published research: Policy implementation in wheelchair service delivery in a rural South African setting. Surona Visagie, Elsje Scheffler, Marguerite Schneider *African Journal of Disability*; Vol 2, No 1 (2013), 9 pages.

Sunette Wessels: Occupational Therapist



Sunette presented service delivery concerns through a lens of rural wheelchair service delivery, stemming from her extensive experience in northern KZN.

Concerns raised	
Travel	<p>15% of poor households are 1 hour travel time from clinics</p> <p>Many clients take ½ day to find access to a vehicle for transport to service</p> <p>Cost of private/bush taxi is prohibitive</p> <p>For many rural wheelchair users there is no transport and no path to access the main road</p> <p>Peer group support is difficult to set up because of cost/distance constraints</p>
Seating services	<p>Most clinics cannot provide a seating service</p> <p>Rural hospitals differ across provinces in terms of service delivery</p> <p>Few hospitals have trial chairs and sizes in stock and spares (don't have storage capacity)</p> <p>Tendency to purchase folding frames with budget to service more people in need – difficult to justify a wheelchair which costs 2-4x more than folding frame. Folding frames also delivered more quickly –individualised can take 6-18months</p> <p>With a small turnover of 6-7 issues per month keeping stock of all sizes, types and other specialized components become problematic. The bigger the variety of wheelchairs the bigger variety spare parts is needed.</p>
Wheelchair use + design for local environment	<p>KZN DoH issued 3350 wheelchairs throughout the province during the 2013-14 financial years. At the end of the financial year, there were 3214 people on waiting list for wheelchairs and 970 for buggies.</p> <p>Looking at the 31 wheelchairs retrieved during the last 6 months, 17 were used for less than 3 months (11 users died and 6 improved) another 5 were used for between 4 and 6 months (3 users died and 2 did not use it). This</p>

<p>Capacity of personnel</p>	<p>further complicates the individualized prescription and ordering if it takes longer than six months to arrive.</p> <p>56% of wheelchair needs are met by returning old wheelchair: clients are encouraged to come in for repair to wheelchair (rather than emphasis on clinical follow up. In this way unused wheelchairs are often located and able to be returned for re-issue</p> <p>There remains resistance to the use of wheelchair that <i>“doesn’t look like a wheelchair should look”</i></p> <p>Consider the suitability of wheelchair designs when temperatures soar to over 40deg</p> <p>Inability to communicate him mother tongue client compromises depth of assessment</p> <p>People prescribe who have never seen the client before</p> <p>Access to regular community level therapists – however there are high implications for needing to train and mentor/supervise every year and affects ability to grow and develop services</p> <p>A complication of high turn-over of staff and with wheelchair budgets not being ring-fenced, it frequently happens that by the time the hospitals new therapist learn about the supply chain management process, half of the budget was removed as it went untouched for 6 months</p>
<p>Positives</p>	<p>Budgets do get increased annually if need is found to be greater than budget</p> <p>21 wheelchair repair sites throughout rural KZN – but do not always have the equipment to help, but users are helped on walk-in basis</p> <p>Most providers do know about tension adjustable backrest, amputee bracket and thicker tyres</p> <p>Budgets are allocated to the hospital and are not centrally managed</p> <p><i>“Things are better than 10 years ago”</i></p>

Questions and comments following questions after speaker input:

1. Call for more training in appropriate wheelchair service delivery at undergraduate level health professionals. Elsje explained that WHO training is at appropriate level to be introduced at university level (undergrad) – can be absorbed into the curriculum across years
2. Participants were informed that the physiotherapy curriculum re wheelchair services is currently being updated HPCSA
3. National DoH undertook to update the Standardised provision of assistive devices document to align it with shortfall outlined by Elsje. Do H acknowledged the struggles

from 2009-2011 due to transitions, but affirmed that in the past 2 years it is picking up with waiting periods reduced to 4 months for a standard folding frame

4. Voiced the need for partnership with NGOs, donors and universities in moving ahead.
5. NB **Debate around inappropriate donor chairs and long waiting times was raised and deemed to be unacceptable to wait for 3-4 years for a chair**
6. Discussion around donor chairs and Maluta's account of the complicated and sensitive political inter-governmental engagement affecting this was raised, as was increased awareness around appropriate wheelchair services which has increased the demand across SA for wheelchairs.



Session 2



Jacques Lloyd: Peer group trainer/wheelchair user

Jacques shared his passion and experience of using skilled, **experienced and trained** peer group trainers (PGT) to contribute to the support and services offered to wheelchair users. He offered ways in which this group can add value to service provision to users.

Jacques voiced his experience that users have limited understanding of their own disability which creates a huge part of the problems they are experiencing. This is exacerbated by both lack of skills and discrimination within society.

According to Jacques, *“it is important to train people with disabilities and develop their ability to make a difference in their communities and provide a support system for clinicians, to cover wider areas”*. Jacques encouraged participants that training can take place under a tree, in a group, one on one, that **experienced and healthy, active people** with disabilities can be trained to pass on their skills and knowledge to their peers, in so doing improving both survival rates and quality of life. Jacques acknowledged the support given to peer group training program through Motivation resulting in the development of guidelines for training peer education in SA. PGTs are well placed to support rehabilitation service (rehab time is often short) by training in health issues (skin, bladder care, detection of complications related to poor posture); training in transfer techniques, sexuality and relationships, offering social and emotional support over time once the person is discharged home. Ultimately they may serve as peer educators in their community, disability awareness and rights and acting as referral agents, informing families and communities. Jacques shared sites of impact including Western Cape Rehab Centre, Meulmed, Tshwane Rehab, APD (incorporated broadly) and Zithulele. Training of peer supporters/educators has been extended beyond the borders of SA to include Lesotho, Uganda, Malawi and Mozambique.

He expressed concerns users commonly have with regard to devices: Transport of folding chairs with rigid backrests; lateral supports complicating the ability to transfer and pick up things.

Jacques finally challenged participants to support the integration of qualified peer supporter; to identify suitable people with disabilities to become peer supporters, to enable them to reach and educate people with disabilities, family members, helpers and caregivers.

June McIntyre: Educator/Occupational Therapist/wife of wheelchair user



June raised the ever important underlying issues guiding services: human rights and ethics, reminding participants of the importance of upholding these, yet at the same time acknowledging the difficulty in enforcing them.

June raised the question: *“Is seating the problem? Or is the system the problem?”*

In speaking about barriers to access, June emphasized that there were many factors impacting users and that ‘bestowing rights’ is not enough. She reminded participants of the multiple role players involved from taxi operators to social workers to police, medical aids to wheelchair users and teachers.

June shared some thought provoking cases/photographs illustrating ways in which wheelchair users experience barriers e.g. pathways that cannot accommodate a wheelchair wider than 10”, a person carried up and down the hill from his home to where his chair was kept (4 hour journey to get to hospital, sleep in outpatients in order to get service) a child being taken out of her wheelchair by her granny who is afraid she will fall off to a case where a wheelchair is buried with a user to avoid passing on the ‘bad luck’.

June asked: Is education going to sort out service provision: who is our wheelchair user? June shared a story about a local induna (affected by peripheral neuropathy, no feeling, diabetic ulcers, arthritis knees) – therapist had a little money left for a chair for him versus another child with severe postural needs for a specialised wheelchair, *“this man told us that if he didn’t get the wheelchair he would make sure that no health workers would not send children to the clinic. After he got his wheelchair, children came out of hiding to access services”*. This type of situation naturally raises questions around ethics and the factors affecting service provision.

June urged all service providers to continue to develop **ethical competence** in practice and service provision including sensitivity, judgement, motivation and action.

June spoke of the challenges in providing continuity of service caused through having personnel doing community service constantly changing.

During discussions, June responded in terms of the difficulties incorporating training into already over-stretched undergraduate academic programs for therapists (who were also often more interested in passing exams at this stage). However, she did indicate that teaching at UKZN had been adapted in line with current training.

Training Discussion

Before lunch Margi Linegar facilitated input from participants following small group discussions (groups’ diverse participants) around wheelchair related training across all levels (including users, parents, health professionals, students, caregivers, grassroots workers etc.). It included **sharing**

- experience of existing training (participants were invited to complete a questionnaire around wheelchair service training known personally to them)
- gaps or concerns around training
- ideas to improve training moving ahead.

Awareness raising, practical skills training and capacity building was included in this discussion.



Feedback resulting from small group discussions around training

Concerns/gaps training	Ideas/suggestions to improve training
<p>Training across different regions People not very aware of availability of training Training is often not presented in client/carer's language Rural and urban areas are not treated the same Lack of services to large areas resulting in lack of knowledge about disability Who determines specs for wheelchairs? A lot of duplication around disability sensitization during capacity building which is not accredited (although can still be useful) Insufficient awareness on disability and devices Northern Cape and Free State – poor wheelchair training Funding of training in early identification and support Inaccessible expensive training/inadequate training Poor advertising of training Misinformation about course Not enough basics of seating offered at university level Parents don't know who to access or ask Technician training difficult to access/ refurbishment of devices at local centres suggested</p> <p>What is trained? Training often product focused (how to fit client to wheelchair instead of how to fit wheelchair to client). This training often doesn't give basic principles of seating but rather teaches selective principles based on what product can provide</p>	<p>What is trained? Get general information out about availability of different types of devices Address ignorance around disability Introduce more awareness campaigns and disability sensitization in communities to get message out Mainstream awareness and knowledge at all levels Define what is a disability and who is responsible for training Need to extend training to include the Children's Act Training must include both knowledge and attitude Accessibility training other disciplines Repair of wheelchairs Need more training for access and affordability of access Barrier free access Medical aid benefits</p> <p>Who does training? Device suppliers are responsible for training in use Training in basic seating should be offered at university level; not accessible to those living in rural areas Need dedicated funded seating training organisation – specialised decentralised seating clinics</p> <p>Who is trained? Ask 'what is a disability?' 'Who is disabled?' who is responsible for that' – the rest follows... Knowledge, skills and attitude training to be more broadly disseminated and not held by a few</p>

<p>Not enough basic sensitization to disability within the community to make lives PWD more acceptable</p> <p>What about universal access/barrier free access training to involve non-health professionals e.g. architects, engineers</p> <p>No official SA training on how to make buildings more accessible</p> <p>Too much focus on 'health' rather than 'disability' focused training of users</p> <p>Not enough training in use and care of devices, need more outreach clinic services</p> <p>Not enough training and support for parents</p> <p>Lack of product training especially in newly available products</p> <p>Lack of training in handling child abuse and the child protection register</p> <p>Who offers training?</p> <p>People with disabilities insufficiently used in training</p> <p>Lack of clarity about whose responsibility training is?</p> <p>Who is responsible for training on new products and how to use them?</p> <p>Not enough knowledge amongst the role players about different types of wheelchairs</p> <p>Lack of transfer skills in how to get into a car and how to store device in car/</p> <p>No therapist training mobility skills to clients/caregivers</p> <p>Huge attitude shift needed to move therapists from old types and methodologies devices- they stick to what they know</p> <p>Insufficient peer group training to support therapists</p> <p>Who is trained?</p> <p>Lack of training of transport companies</p> <p>Parents, caregivers and children with disabilities not trained</p> <p>Not everyone wants to sacrifice leave to do training in seating</p> <p>How to train? Follow up to training</p> <p>How to realise training to non-therapists</p> <p>The follow-up and reinforcement of caregiver training is a major gap</p> <p>The need for ongoing training and exposure to various wheelchair seatings</p>	<p>Government platform- partners to keep government accountable</p> <p>Therapists need training on devices which can be prescribed</p> <p>Engaging CHCW with standardised level of care for identifying child with disability</p> <p>Training of all health care workers at all levels on eligibility, follow up, identification of secondary complications</p> <p>Focus on infrastructure – roads and homes for children with disabilities</p> <p>Increase of social worker training in disability sensitization</p> <p>Increase of training to government – around provision of donor wheelchairs</p> <p>Training across the board re the importance of early intervention and on referral pathways</p> <p>Educate politicians around donor wheelchairs(appropriate screening and use of)</p> <p>Extend training into curriculum of architects/engineers on accessibility needs</p> <p>Extend training of peer group trainers to support service providers</p> <p>Train transport drivers in transfer techniques</p> <p>Clarify role of peer group trainers</p> <p>Follow up and reinforcement of training</p> <p>Is there a way to bring seating knowledge closer to the ground?</p> <p>How to train?</p> <p>Local community radio stations and newspapers to raise awareness and provide regular info on disability issues</p> <p>Use of social media to increase awareness</p> <p>Networking in industry to collaborate, raise awareness and increase knowledge</p> <p>Documentary demonstration of wheelchair use, service provision at appropriate outlets</p> <p>Repeat training of staff and caregivers- ongoing training is required to build capacity (3 months?)</p> <p>Find ways to identify and stop the distribution of cheap wheelchairs</p> <p>Link up with NGOs like Malumele Onward that provide devices and therapy in rural areas</p> <p>Regulation and monitoring of training</p> <p>Recommend a centralised body to oversee wheelchair training</p> <p>What are the standards or qualifications required to train this?</p> <p>Develop/implement competency assessments</p> <p>Establish guidelines around training</p>
--	---

<p>Monitoring of training /service</p> <p>Confusion about where we can report problems to...lack of a watchdog body to address problems</p> <p>No coordinated structure of all the support that can be offered</p> <p>Not sufficient early referral from birth of child with disability</p> <p>Some training is not monitored, regulated or standardised</p> <p>Need regulation of disability awareness training</p>	<p>Training workshops should be CPD incentivized for health professionals</p> <p>Must ensure trainers are skilled and knowledgeable to train</p> <p>Develop standard curriculum for community health workers/facilitators and training to fill gaps</p> <p>Training needs to be included in government structures and systems and standardised</p> <p>Training can be requested from suppliers of devices on tender</p> <p>Training must be regulated and monitoring and evaluation done</p> <p>Standardised training in repairs including all items on tender</p> <p>Being able to refer for seating</p> <p>Need regulatory body to regulate disability sensitization training</p> <p>Policies need to be applied more correctly</p> <p>Volunteer training with some form of accreditation</p> <p>Private companies need to collaborate into a coordinated wheelchair provision service and training for the public</p>
---	--

Formal training e.g. Department of Health basic, intermediate and advanced seating courses is fairly widely known, so participants were also encouraged to share about less formal types of training or capacity building initiatives within their discussion groups. Registered participants were also invited to complete a training questionnaire (via website) and to submit a simple questionnaire for a collation of training opportunities

Existing training named by participants (this was compiled from 20 participant questionnaires submitted at end of day)

This was information sought on a simple questionnaire/collected after event

- ✓ Wheelchair service delivery: Basic professional level (WCRC/DARE Consult)
- ✓ Wheelchair service delivery: Intermediate professional level (WCRC/DARE Consult)
- ✓ Wheelchair service delivery: Advanced professional level (WCRC/DARE Consult)

These courses are offered in the Western Cape, Gauteng and Eastern Cape and even the WC courses are not only attended by WC therapists but by clinicians and wheelchair service practitioners from all over SA, with a small number of delegates from other African countries. Ad hoc courses are arranged on request.

- ✓ WCRC- technicians training (WC)
- ✓ Basic training for non –professional home based carers –posture, adjustments; prevention of secondary complications
- ✓ CE Mobility
- ✓ NDT training
- ✓ Dare Consult (E Scheffler) – Cape Winelands Intermediate seating supervised monthly over 1 year period
- ✓ University – universal access (WC)

- ✓ Shonaquip (WC) e.g. Fishoek/Simonstown magisterial district aimed at practitioners and parents.
Buggy training (including assessment and basic seating principles/measurement/fitting/troubleshooting/ repair/access to tender); product specific training across SA where devices are prescribed
- ✓ KZN: 3 hospitals have therapists with training who provide some informal training to new therapists; KZN wheelchairs do annual courses in the province
- ✓ UKZN dept. OT/PT/OTA/OTT/PTA/PTT/SW/CCGs/caregivers/users/orthotists/students- by June McIntyre and CE Mobility; done wherever the need is re product training; disability awareness, mentoring, wheelchair maintenance (over last 14 years); seating practitioner skills, user mobility skills – trying to train trainers amongst the therapists. Training via Telemed on occasion, tailored training for schools if they identify a problem (package put together)
- ✓ Ottobock – product training to health professionals 1x or 2x annually; to end users (Midrand rehab) done by Ottobock Certified Health professionals OT and OB product specialist
- ✓ WC training of support staff at special school (needs to be requested)
- ✓ University training: does this include hands on training?
- ✓ Uhambo training
- ✓ SA Society Physiotherapy
- ✓ UCT – universal accessibility
- ✓ Paarl school (Mark) educates learners on daily basis with wheelchair mobilisation
- ✓ CP Association /physios

After the lunch break, two speakers presented input to participants both focusing on the use and importance of assistive equipment to support early intervention programs.

Nolitha Vena Eastern Cape NACCW



Nolitha presented the efforts of the Isibindi (including training of disability facilitators) initiative by NACCW to meet the needs of children with disabilities within the NACCW framework/model of community based caring for children across the 68 sites throughout the 9 provinces of SA. Currently over 70 000 children are under NACCW child and youth worker care. In 2007 150 children with disabilities were included in NACCW program. Nolitha did share with participants how underprepared child and youth care workers were, and

highlighted the importance of training for disability facilitators to be able to work with these children within the context of early intervention.

Severe challenges included the repair and maintenance of devices, the challenge of providing reviews of children with devices more than once per year (usual standard much more often – every 3-4months). She also discussed the cultural beliefs, lack of community disability awareness and perceptions affecting the lives of children with disabilities. Another challenge experienced was the very long waiting lists in public hospitals, many of which are also not easily accessed by wheelchair users (some travel 30kms to the hospital), Nolitha raised the issue of early intervention and capacity building of child and youth care workers as disability facilitators at grassroots level.

Ruth Stubbs Teaching background/inclusive education/Shonaquip



Regional Wheelchair Services Roundtable 24 October 2014

Ruth reiterated the human rights approach raised by other speakers. She decided not to do her original presentation which had also focused on early intervention with assistive devices in order to avoid duplication of speaker input. Instead she raised the important issue of 'what happens next when a child in a device' is part of the education system... emphasising the importance of training 'non' health professionals to understand the benefit and importance of appropriate devices, how to position the child, use and care for the devices in such a way that promotes the full inclusion of the child with a mobility impairment. The issue of very limited training of social workers (20 minutes in disability sensitization!) was severely insufficient to promote full understanding and needs of children with disability. Ruth urged participants to consider: *"If I, as a teacher, don't know how to position the child, how will they become productive and good members of society?"* In so doing, she urged participants to consider the extension of training and awareness raising beyond the 'wheelchair service provider'.

Open Space Discussions:

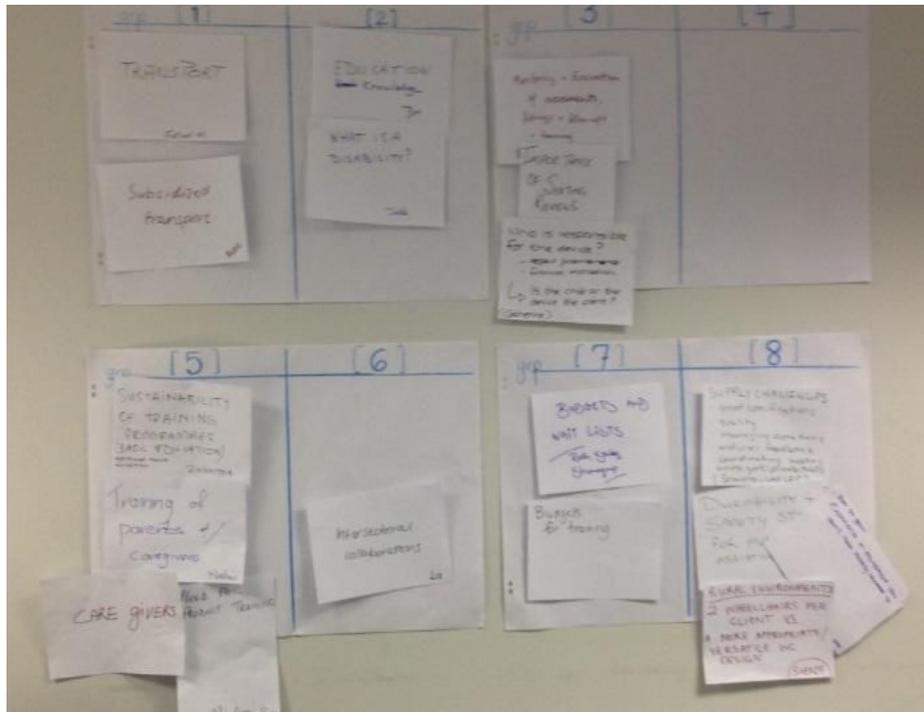


Following the speaker inputs, Miné Campey (seating practitioner, Shonaquip) introduced the concept of an 'open space' discussion and participants were invited to write their topic for discussion on a piece of paper. These topics were then combined with other similar topics so that 8 different discussion groups could meet, each with a host and a scribe to

be able to record important discussions and feed back to the larger group. Open space technology relies on 4 principles to guide discussions:

1. Whoever comes in (into the group) is the right person?
 2. Whatever happens in the only thing that could have?
 3. Whenever the discussion starts, it is the right time, when it's over its over
 4. The law of 2 feet (4 wheels)- move on when the discussion is over
- A person proposing each topic and a scribe were asked to host the group discussion and to ensure feedback could be given to the large group after the discussion.

Topics raised by participants for discussion



Feedback open spaces discussion:



Feedback was taken directly from flipcharts provided by scribe of each discussion group. No attempt was made to alter or analyse any feedback.

Group 1 Ann Bullen Transport

- ✓ People with disabilities (PWD) need to be employed within the transport sector at all levels and in particular at decision making levels
- ✓ Present issues – safety is most important one, lack of empathy; access as to where services are available; safety issues (My Citi and Dial a ride); should not be charging of carers; lack of capacity to deal with emergencies; drivers untrained to deal with disability; lack of equity to where services are available; they are not always available to all areas; My Citi – tourism prioritised; may have been better to have transport on important routes for function e.g. home affairs
- ✓ PWD employed within decision-making capacity; more transparent tender processes (Rene –experience in applying for tenders, BEE, level 4 applicants be able to move up list); increase competition, bring in more role players; opportunities for job creation; regulation around implementing regulations in place. Remove monopoly.
- ✓ What stops people developing similar services. Competition commission won't have a problem with other services (will people have to pay); getting a permit (why do I want to start a business, treated as if you are brain-dead) Dial a Ride is only R6 per km - PWD cannot afford Rene's routes (private transport service for wheelchair users): R24 per km
- ✓ Huge opportunities for job creation in this sector, especially in rural areas
- ✓ Enforcement of safety regulations: liability, driver competence; roadworthy certification; insurance passengers
- ✓ Coordinating agency between departments needed

Group 2 Jos and BJ van den Boogaard Education and knowledge - What is a disability?

- ✓ Importance of establishing 'What is a disability?' A person cannot function to their optimum because of barriers – social, environmental etc.
- ✓ Important to introduce training widely around disability issues (across society)
- ✓ Social and attitudinal barrier. Nurses that don't allocate wheelchairs because of some protocol within the clinic, wheelchairs are standing there and can be used. Training and education – knowledge should be part of curriculum – put pressure on tertiary education to include into all parts of curriculum, within communities and correct knowledge about disability. Regulate training; happens by many different people, don't understand the concepts, training needs to be done by the 'right' people

Group 3 Maria Repairs and follow-up

- ✓ Spoke about training. Training of repair staff and monitoring; how do we make sure the knowledge is update; certification doesn't mean competence; need a system to monitor people who are abusing devices- ? pay something towards it, show some responsibility; look at ways to empower people to replace the used part – recognising when there is a problem
- ✓ Who is the client? The wheelchair or child? Need a way to track our child. Raised issue of DOE seamless number, can be tracked through province. CWD (severe) – if moving between provinces, they need to be tracked with their devices. E.g. in a special centre; fundraised for a device; as NPO what happens to repair; look after child and device instead of just device
- ✓ Regular **seating** clinics: know that it is their responsibility to go and have device reviewed; so 2ndary complications don't develop
- ✓ Repairs: who gets to do repairs when damage is caused by negligence or abuse?
- ✓ Monitoring and evaluation of training

Group 4 Candice Access to equipment and devices in schools+ Distribution of wheelchairs to hospitals and NGOs + accessible services

- ✓ Mobile community outreach services
- ✓ Should there be a tender that provides the same service in different ministries? E.g. with respect to tender in DOE and DoH
- ✓ Budgets are specific in depts.: hearing aids (DoE); wheelchair (DoH)
- ✓ Rules and laws within depts.
- ✓ Government is fragmented
- ✓ NB PACSEN: make use of what is available; don't re-invent the wheel and join a movement with the same aim/goal

Group 5 Capacity building and empowerment

- ✓ Device specific training
- ✓ Target: community serves in health professions
- ✓ Teachers, family members, carers, peer education – involve stakeholders in implementation
- ✓ Partnership between government and NGOs
- ✓ Volunteerism
- ✓ Training should take place at least 4x per year
- ✓ Focuses on training; capacity building and empowerment; training accredited or recognised.
- ✓ What is training? Giving skills and empowering carers and disabled peoples; every health professional; teachers, family members, carers. How will we implement this training?

Outreach through clinics, invite different people like home based carer offer training; could be in schools, everywhere PWD are found. Wont target everyone; sustainability – even if can only target 5 areas in WC, follow up, offer the best quality and make it sustainable, able to be passed on to generations.

- ✓ Who does this? Health professionals offer training to non-health prof, then cycle goes on – maybe not enough therapists, home based carers to empower one another, peer trainers from within this group
- ✓ These services will need funding – partnerships bet NGOs and govt. Develop a good relationship between NGO and govt. Volunteering can ---so much can grow from us, grow from this – can get out from “I need to gain something’ – it changes the world, and you benefit
- ✓ Outcome measure of effectiveness – we don’t really have standardised outcome measures; poster pictures before and after; qualitative questions; participation – we asked what difference it has made in their lives

Group 6 Intersectoral collaboration: Nicky Seymour

- ✓ Goal would be to have open resources, there should be transparency of resources, sharing of resources, open access.
- ✓ The mandate to be inclusive exists; requires coordinated agency; from community to central and back to community
- ✓ Lots of different sectors involved in seating provision and people with mobility impairments. Pockets of groups working together; differs across provinces; no consistency; biggest impacts, there are resources but not allocated in right direction for benefit. How do we get them allocated in the right directions; appropriate inclusive policy. Made a diagram – see flipchart. What are the sectors that should be engaged?
- ✓ DOH and DSD, DoE, Dept. of Transport; Housing; Sports and Recreation; Infrastructure; Children with disabilities; Geriatrics, Nutrition. Different levels, at community level you see needs not being seen. Pockets of collaboration need higher level.
- ✓ Quaternary level: collaboration at high level necessary. Get key representatives into something existing, place a body underneath this – NHI – national rehab management (bigger picture than just mobility and assistive devices – the mandated body to take this on, we need them to engage with these different bodies; get resources allocated to this body; some control but engaging across
- ✓ MADAC: Fits under this with a focus on mobility and assistive devices. Didn’t have a high mandate so it dissolved; drawing this body back in. Huge activity globally – can draw the international knowledge in. Do you have one or provincial level ones that can then be advisory bodies to the rest of the province, ensure guidelines are being followed, make sure that there is coordination at levels.

Group 7 Budgets and Waitlists Andrea/Ruth

- ✓ WCRC represents an ideal system: no waiting lists, order in bulk, 3-4 weeks waiting time; option to trial a device. WCRC serves as the ideal, came with huge fighting; advocacy; raising awareness and training; get to know the people who hold the money purse; bang on their doors, get people behind you; knock on their doors; ring fence your budget. Many say don’t have budget 50 000; when have 30 000 have meds etc., order before they use the budget.
- ✓ Start with one person getting appropriate wheelchair, you will make inroads!
- ✓ Get to know who to approach within the hospital
- ✓ Dedicated ring fenced budgets, raise awareness and highlight the plight
- ✓ Service provider product and seating training

- ✓ Must be able to quantify need.

Group 8 Sunette

- ✓ Reported a great discussion, talking about the product – **supply chain, the life cycle of the device**
- ✓ Budgets won't grow until they are overspent; tenders; able to get basic; access to suppliers and services (would like to know how do you access supplier if no longer on tender)
- ✓ How to get info and capture data – user maintenance or poor quality parts
- ✓ People and relationship and communication with procurement office can make more of a difference; follow up progress; use information to influence management
- ✓ When pushed to give numbers, doesn't always reflect the quality of the device
- ✓ Need product training by suppliers
- ✓ Prescription: need to keep the cost for user in mind
- ✓ Access to spares (and also to devices no longer on tender)
- ✓ Manpower needed for repairs/dismantling/recycling
- ✓ Inconsistent SCM- institution based budget/provincial /O&P based budget
- ✓ Need to get feedback to suppliers on problems experienced
- ✓ Need management insight into reasons for prescription
- ✓ Motorised wheelchairs: how to access and criteria for prescription needed
- ✓ Indicators for rehab services: do have quantitative, not qualitative
- ✓ Durability: lifespan of wheelchair – years vs activity level vs use vs environment
- ✓ Donations: spares/repairs (to donate on prescription)
- ✓ quality /durability standards – do we need to develop new/can we build within current standards



Thought provoking issues raised from participants during the day (Parking lot issues)

- Should we always be thinking about wheelchairs? What about movement?
- What about access to transport?
- What about incorporating basic level wheelchair training into University curriculum?
- What is the maximum length of time (ethically?) acceptable to wait for issue of a device?
- Are we managing the donation of wheelchairs (? as per recommended guidelines)
- Is government going to train para –professionals in the light of the shortage of therapists (to deliver wheelchair services)?

- Will outreach clinics be brought back where services were taken to clients? (raised by participant on evaluation form)

NB Feedback from the day's events was shared following the 'open space' forum. It was initially hoped (in the planning) that participants could reach a position of a 'Call to action' but this was (in hindsight) unrealistic given a full program, different levels of participation and experience, varying stakeholder needs and constrained time available to reach a conclusion.

Mansur Cloete (Uhambo Board) suggested that findings be circulated per email before a decision was made on a 'Call for action'.

Evaluation from participants

Feedback forms were given to all participants but only 1/3 (33 participants) of the evaluation forms were submitted to organisers after the event. This may have been because some participants had left before the end of the afternoon session when participants were invited to submit them. Forms could be submitted anonymously. A further opportunity will be given via the website for people who still wanted to offer feedback on any aspect of the event. Organising staff also did not all complete forms so will also be invited to do so.

1. **Information given about event:** only 5 reported 'low or very low' to this
2. **Organization of event :** 30 of the 33 respondents marked this as 'somewhat high' or 'very high'
3. **Speakers for the event:** All but 2 respondents 'Somewhat high' to 'very high'; one or two said speakers input had too much duplication

General comments:

1. Positives +s

Variety excellent; very informative, relevant and helpful; like broad spectrum of representatives; generally well organised; good variety topics; discussion opened ideas; an interesting day; all speakers offered relevant information; discussion sessions were exciting; enjoyed viewpoints from different sectors; very insightful; lovely platform to stand together with our concerns and work on a way forward; a good start to inter-sectoral collaboration; liked the fact that the open space discussion could pick up topics not covered elsewhere; lots of positive discussion in the groups and can take a lot back to my organization; everyone sharing the same ideas and thoughts; saw how stakeholders can work together, look forward to the future

2. Negatives /possible changes

Want more stakeholders on board; want more government representation (procurement depts.); parking difficult at venue; some overlap in speakers who did not really talk specifically to themes; need to control timing of speakers more; aim and expected outcome not clearly enough stated; not leaving us with substantial solutions; room this size needs at least 1 roaming microphone (promised but not available on the day); late notification of event; would like to have started discussions earlier to enable wrap up before end of day (prefer to email); want larger representation from other sectors; more people with disabilities and contribution from people

with disabilities; would like a contact list from the event to build partnerships; more structure; facilitator needs to be more assertive; more time for afternoon session; could have taken topics to deeper level; would like a follow through to resolution; incorporate management stakeholders; involve more stakeholders that work in the community; too much noise in the venue makes discussion difficult to follow in groups; wheelchair toilet far too small; bring on more procurement depts.; more focus in discussions according to themes; ? Start discussions earlier (makes one feel contribution is valuable and moves things forward)

Topics suggested for a follow-up event:

Product costing; more about what is available in the private sector; durability, sustainability of part and wheelchairs; more about available resources; access in the home for wheelchairs; making wheelchairs more affordable to the vulnerable; transportation; how do we sustain especially in procurement dept. when the tender is no more;

Participant response to ‘Should it be an annual event?’ Overwhelmingly positive response from participants who completed feedback form, although some participants felt that it should be held elsewhere in the country and a few (less than 5) indicated they would like to repeat it in another format (qualified ‘yes’)

Evaluation from Organising Committee

- Adequate funding for the event was lacking which compromised planning and broader national and community participation. Did have sponsorship of venue, stationary, printing and some donations to supplement catering e.g. juice, platters, wine
- Event provided a satisfying and excellent networking opportunity across levels and working contexts. In so doing it created a community of people talking around similar issues.
- Could have benefited from a more collaborative approach to plan/host the event
- Marketing: needed to set up database for marketing broadly beyond own networks, perhaps in collaboration with other participants. Need to encourage more participation from wheelchair users and community based workers and DPOs, perhaps organise transport if needed. An important recommendation is that the event involve more stakeholders especially from government (DoH/DSD/DoE) and procurement officials in any future meeting. This may of course result in the planning of both a bigger and longer event.
- Venue mostly suitable, would have benefitted from more flexibility in moving tables and chairs for small group discussion. Limited number of people could be accommodated in the venue. Access for wheelchairs acceptable, parking arrangements possible for participants not ideal due to central location and starting time of event
- CPD accreditation approved, certificates available at event; attendance certificates for all other participants. Process of registration could have been more efficiently executed.
- Should have clarified purpose and desired outcome/action **more clearly** – what it is; what it isn’t. Important in terms of non-health professionals and expectations. Wrap up session would have ended the day with a more positive way forward/perhaps left people disappointed as it happened. Nevertheless, observed high energy during networking and discussions, people wanted to talk about issues with one another
- Not good representation from Free State; Northern Cape; Limpopo and Mpumalanga – funding may have enabled some travel assistance to ensure greater representation
- Government support and representation difficult to secure early in planning, this limited participation in the event as speakers which would have been beneficial

- Time pressures considerable given one day event, need to consider participant opinion about extending it to 2 days. Ask participant opinion on whether they would travel to Cape Town for a further event/whether they would support a 2-day event
- There was a diverse mix of wheelchair users and service providers. Because issues are sometimes quite different, it was felt using different options in program structure was necessary (and successful to accommodate all) although it is acknowledged that not all sessions will suit all participants all of the time. Any future format might consider including alternative formats e.g. parallel sessions followed by discussion around the expert-led topic. Expert vs novice – different levels of contribution and existing knowledge, could have used experienced participants to be more active in guiding discussions.
- Speakers presented interesting, relevant information which was well received; some degree of overlap inevitable – last two speakers adjusted their prepared presentations accordingly
- It was a challenging task trying satisfy all needs and expectations across the levels/types of participants. Nevertheless still noted high energy and interactive participation across stakeholders, but format can still be modified to accommodate this if event is to be repeated.
It was acknowledged that it is sometimes a difficult balance (requiring sensitive handling), when giving people such a platform for engagement, to bring in so called ‘expert’ opinion to clarify/respond to issues without impacting on/overriding other levels of participation.
- Sometimes difficult to get to answers in this format. Dissemination of information or answers to questions raised is difficult during group discussion if perceive an ‘expert’ is not in the group.
- No problems with catering or cocktail function

Follow up action:

In the short term



- Helenna Makura (pictured right), supported by Shona McDonald, (Shonaquip) will put together a presentation based on the event report and her experience of being a participant at AfriNEAD Symposium in Malawi in early November 2014. It is also important that they in turn report widely on any feedback generated from AfriNEAD about this

initiative.

- **Recommended action:** A practical recommendation by the organising committee to use the momentum raised by the event, is to brief participants as soon as possible on the findings and possibilities for actions going forward (i.e. given both detailed and abridged reports).

At the same time participants could invited to express interest in serving on a **smaller working group to represent the wheelchair services sector to**

meet quarterly as a group and again at annual event
serve as a lobbying body; representative voice from wheelchair sector

help influence agenda and input/format for next joint stakeholder event (strategic /not operational)

plan how best to bring existing seating professionals and non-professional, experienced service providers to work more closely and efficiently together for benefit of users (and yet remain medically and legally accountable for seating provided)

- Consider establishing a **link with one or more tertiary institutions** to provide ongoing backing for this collaboration process: to guide participatory action research + lobbying/policy development e.g. Centre for Rehabilitation Studies (US)/Disability Studies (UCT)
- Findings need to be widely distributed to relevant networks; an abridged report will be sent to Thisability; RUDASA; professional associations; disability organisations; DPOs; NGOs.
- Keep the conversation in the community active via maintaining existing event website <http://wheelchaircon.wordpress.com/>
- NB *Secure funding to support such an event and promote the attendance of delegates from across SA will be of paramount importance to the success of such an event. This will need to be done be actively sought a full year in advance of any follow up function*

Conclusion:

This was a first event of its kind in SA, bringing together stakeholders from across the industry. In so doing, it fostered an exciting, unique 'community' and provided a platform for networking.

Wheelchair users, carers, suppliers, a range of service providers in both state and private or NGO/DPO sectors had the opportunity to listen to one another and experience some meaningful collaboration.

The energy of the group was sustained throughout most of the day, demonstrating that people are motivated to collaborate across levels and disciplines. However, it is acknowledged that it is challenging to meet every participant's need adequately across levels of experience, expertise and expectation.

The event could be viewed as having potential to disseminate information, bridge gaps between novice and expert providers, foster understanding between users, decision makers, suppliers, educators and service providers and generate innovative solutions. Ultimately this joint action could serve the community well by influencing service provision planning at a number of levels and ultimately ensuring quality services for users.

The organising committee recommends that the event continue on an annual basis from feedback received, but not necessarily in the same region, or in the same format, but that any future event incorporate some of the suggestions put forward by participants at this event. Findings from the event need to be widely disseminated and should be considered for incorporation broadly into initiatives for improving wheelchair service provision in the future.



Mansur Cloete, Director of the Uhambo Foundation Board, has expressed willingness to oversee and assist hosts to direct future actions based on findings.

This report was compiled by organising committee Uhambo Foundation based on

- Minutes of planning meetings
- Notes from scribes during proceedings at the event
- Flip chart notes made during discussions
- Post event evaluation of participants and planning committee
- Board meeting Uhambo Foundation: informal discussions post event
- Photographs taken during the event

A special thank you is extended to all participants, speakers, sponsors and helpers for supporting the event, for sharing your stories and voicing your concerns and ideas.