Report:
African Spinal Cord Injury Symposium
And
Launch of the African Spinal Cord Injury Network (AFSCIN)
Gaborone - Botswana
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“Ke Nako” – “It Is Time”

10 December 2015.
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1. BACKGROUND and CONTEXT:

The prognosis for people sustaining Spinal Cord Injuries (SCI) in low and middle income (LMIC) countries is bleak from the onset. A patient with a SCI in Africa has to cope with any number of major challenges across the continuum of care. These include severe traumatic injuries and illnesses, the added challenges of poor evacuation protocols and pre-hospital care, inadequate radiology imaging services and the lack of specialised units, inadequate rehabilitation services and poorly trained staff. This results in poor or limited integration into the community and very little chance of entering or remaining in the job market. The consequence of this is a complete dependency on family, friends and the state, often resulting in the whole family being further trapped in poverty. Mortality rates in LMIC are higher than in high income countries (HIC).

There is an urgent need to address these issues and the associated problems that include:

- Professional skills are limited to a few centres of excellence on the continent
- There is a lack of minimum standards of care
- There is a lack of a systems approach to SCI on the continent
- There is a lack of a holistic, empathic, inter-disciplinary approach to care
- Research is limited and often not appropriate for the improvement of services on the continent
- Resources are few and are often under utilised

Increased coverage and quality of appropriate affordable accessible and integrated rehabilitation services can assist in reducing mortality and morbidity and in turn help people with disabilities to live full, dignified and productive lives in their own communities.

2. AFRICAN SPINAL CORD INJURY SYMPOSIUM

The decision was taken to host a trans African SCI Symposium in October 2014 under the auspices of the International Spinal Cord Society (ISCOS) and with back up support from the Southern African Spinal Cord Association (SASCA). Contacts were established with Benin, Botswana, Burundi, Cameroon, DR Congo, Ethiopia, Kenya, Lesotho, Madagascar, Malawi, Mauritius, Morocco, Mozambique, Nigeria, Rwanda, Sudan, Swaziland, Tanzania, Uganda, South Africa, Zambia and Zimbabwe.

An organising committee with members from SASCA and the ISCOS education committee was established.

Botswana was selected as the venue as the Princess Marina Hospital has a functional SCI unit and Gaborone is geographically close to South Africa. Members from the Princess Marina Hospital in Gaborone were co-opted on to the organising committee.

It was envisaged that the Symposium would act as a platform to:

- Share models of best practice from across Africa
- Provide training appropriate to the needs of the African continent
• Promote lesson learning through sharing of successes and failures
• Support the establishment of specialised spinal unit services on the continent
• Facilitate the creation of country specific spinal cord injury organisations
• Foster research and clinical excellence
• Duplicate good examples of care across the region
• Network with governmental and non-governmental organisations, academic institutions and other service providers
• Link professionals into existing SCI professional networks affiliated with ISCoS

3. THE AFRICAN SPINAL CORD NETWORK (AFSCIN)

The Symposium was also viewed as an ideal platform to discuss the formal establishment and launch of AFSCIN as a mechanism to address common challenges across the continent. The logic being that the creation of a collective will strengthen the process of developing strategic guidance for service delivery and liaison with key stakeholders in Africa, as opposed to individual efforts by each country.

4. SYMPOSIUM PROCEEDINGS:

At the commencement of proceedings there were 75 preventativees from 8 countries, including Botswana, South Africa, Madagascar, Zambia, Zimbabwe, Namibia, Malawi and Tanzania. Representatives from Cameroon, Madagascar and Congo encountered visa problems en-route and had to return home.

The symposium was joined by ISCoS members and Education Committee representatives from South Africa, Ireland, USA, Belgium, UK and Netherlands.

5. DAY 1:

5.1. INAUGURATION:
Proceedings were opened by the Assistant Health Minister of Botswana, the Honourable Dr Alfred Madigele.

The honourable minister indicated that it was a privilege to open the African Spinal Cord Injury Symposium as it was the first of its kind in Africa, to focus specifically on SCI injury management in Africa.

He highlighted the fact that management of SCI in general imposes a heavy burden on the health care system. This is due to the high care costs associated with specialised care and rehabilitation services, the need for home-based care services and constant reviews after discharge and the life-long follow-up required. Furthermore, that the family and community at large are not exempted from the burden of taking care of people with SCI. The global financial burden as a result of management of complication of SCI is estimated at 32% of the medical costs over the first two years following an SCI.
This results in poor integration into the community and very little chance of entering or remaining in the job market. The consequence of this is complete dependency on family, friends and the state, often resulting in the whole family being further trapped in the poverty cycle.

Therefore, AFSCIN can provide opportunities for coordinated multi-sectoral actions within and between countries to successfully manage and prevent complications of spinal cord injuries, premature mortality and further disability among our populations. He further iterated that improved health conditions are a critical benchmark to measure the impact of efforts by our Governments, civil society organisations as well as international agencies in improving the lives of our people. The attainment of good health conditions represents not only a broad vision and a global aspiration, but an overarching framework for guiding development activities and investment in the region.

Dr Madigele emphasised that the attainment of good health in communities will be seriously compromised if issues that continue to challenge the health care system are turned away from or not confronted. One such challenge is SCI management which has increased significantly as a contributor to the growing burden on the health care system.

When implemented fully and effectively, the interventions recommended by a program such as this will greatly increase knowledge in the management of SCI and ultimately reduce the socio-economic impact of the complication of SCI in the respective health care systems. He was also encouraged to note that the majority of countries participating here today are prioritizing SCI care, management and rehabilitation programs.

The honourable Assistant Minister acknowledged that although Botswana has significantly improved the lives of people with SCI, the challenges highlighted still remain apparent for Botswana as a country and Africa in general.

He indicated that a renewed push to prevent and control the management of SCI requires that governments and leaders in African countries, with the support of civil society and international organisations, should embark with courage and conviction upon a sustained collective effort to effectively implement their commitments under this new initiative of AFSCIN. Africa must unite to win the war on spinal cord injuries.

5.2. INTRODUCTION

Introductory comments were made highlighting the aim of the suggested AFSCIN. Further comments included the acknowledgement of the severe strain on under resourced health services in Africa as a result of the severe burden of disease in the continent and the recognition that services for people with SCI cannot be seen in isolation.

5.3. ROUND AFRICA IN 120 MINUTES

This session allowed each country to present the challenges and successes in relation to the services and opportunities available or denied to people with SCI. Reports were presented by representatives from Botswana, Cameroon, DR of Congo, Malawi, Tanzania, Zimbabwe, Zambia, South African and Madagascar. Some reports contained some epidemiological information.
There were certain common threads amongst the presentations, as some countries have started with projects to improve services for people with SCI and others have only realised the need to address the situation. However, the state of affairs in countries that were not represented is unknown. In sharp contrast to this, some countries that indicated that services are non-existent and that they are relying solely on the services of peer supporters.

It is clear from the presentations that several countries work closely with NGO services and other service organisations. There were enormous benefits from the close cooperation from organisations such as Spinalis, Handicap International, Stoke Mandeville and Motivation Africa to name a few. It is important to maintain and strengthen these relationships.

The need for community based rehab services was acknowledged but it currently seems to be limited, leading to poor community integration. This situation is further exacerbated by the fact that services for people with SCI are seen as the responsibility of the Health services and that holistic services delivery from other sectors such as Housing and Education are nearly nonexistent.

Accessing consumables such as catheters are a near impossibility especially if consumers are not living in major towns. Catheters are often used for long periods or even shared between consumers. It appears that there is no system in place for the distribution and provision of such items.

Supply of appropriate wheelchairs remains a huge challenge and many countries rely solely on donated wheelchairs. This lead too many people being seated inappropriately and thus the development of secondary complications. As the wheelchairs are being donated, the repair services are hampered due to the lack of spare parts.

Supply chain challenges further complicates the delay in wheelchairs provision. Processes are long and there is unacceptable waiting periods before a chair is issued. Often quality of a wheelchair is ignored in favour of a cheaper wheelchair.

Some epidemiological information is available from a few centres but it appears if no one country has a data base. Most of the papers suggested that road traffic accidents and falls lead to the majority of injuries but that more attention should be given to the incidence of SCI due to TB. It seems that this information is then not utilised to prevent injuries and to improve services.

Evacuation processes are problematic and in many instances private and public transport are used. It was suggested that it might explain the higher incidence of complete injuries in some studies.

The reports suggested that it is crucial for each country to have a national strategy for the holistic management of SCI that should be developed in close cooperation with consumer groups. The strategy should contain details on the standard of care at the various service delivery points. It is further imperative that awareness around the comprehensive management of people with disability be raised.
User groups are functional in South Africa, Malawi and Tanzania. It was emphasized that services cannot occur unless there are close cooperation between the consumer and health workers.

5.4. **SPECIFIC TALKS**

Day 1 culminated with a number of talks on initiatives around the world that may have a bearing on AFSCIN.

5.4.1. **International Spinal Cord Society (ISCoS)**

ISCoS is an organisation for those committed to improving the lives of people with SCI. It works closely together with the WHO. ISCoS fully support the goal of the WHO Global Disability Action Plan of achieving optimal health, functioning, well-being and human rights for persons with disabilities by striving:

- to remove barriers and improve access to health services and programmes;
- to strengthen and extend rehabilitation, habilitation, assistive technology; assistance and support services, and community-based rehabilitation;
- to strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services.


ISCoS and WHO work together to lobby governments for change in policies and this culminated in the drafting of the International Perspective on SCI Report (IPSCI).


ISCoS further

- provides education to improve care and rehabilitation
- ensure ISCoS collective expertise is used in natural/war disasters
- Uses the IPSCI report to lobby policy makers for change

A major resource from ISCOS is the E learning website. It is for medical and paramedical professionals working in the field of spinal cord injuries. It contains learning modules for the whole team including doctors, nurses, physiotherapists, occupational therapists, assistive technologists, social workers, psychologists and peer counsellors. The modules are intended for medical and paramedical students and junior clinicians. Others who have yet not assimilated sufficient knowledge on comprehensive management of SCI will also benefit from the information available. The learning content is presented using combinations of presentations, interactive activities, case studies, videos and self-assessments. The modules have been created by the world's most experienced academicians and clinicians. There is no cost associated with accessing the modules.

**E learning** [http://www.elearnsci.org/](http://www.elearnsci.org/)

ISCoS have been instrumental in developing data sets in SCI. This was done in an effort to standardised data collection around the world.

The process followed was as follows:
Core working group formulates dataset
Seek feedback from professional bodies
Validate
Get endorsed
Train users

Some examples are:
- SCI upper extremity
- SCI urinary tract imaging
- SCI quality of life
- SCI activity and participation
- SCI skin and thermoregulation function
- SCI endocrine and metabolic function
- SCI pain

Data sets: http://www.iscos.org.uk/international-sci-data-sets

ISCOS has developed networks with various organizations and bodies around the world. This was all done to improve cooperation and networking whilst endeavouring to improve the lives of people with SCI. The table below reflects the networking model.
5.4.2. Cost recovery system – Vietnam

This presentation served as an example of cost recovery model.

Vietnam is still classified as a transition economy with strong economic growth and this is seen as the engine to reduce poverty. Some aspects of health care are being taken care of by government financing like primary care and prevention. However there is a tendency towards financial disengagement in curative health care and rehabilitation.

Estimates and socio-financial indicators among patients at the Spinal Unit showed that approximately 30 % of the patients and their family members declared that they encounter serious financial problems during their initial medical and rehabilitation treatment.

In general, around 25 % of patients had some kind of insurance cover.

The care in the Units is provided through a protocol of treatment with a given length of stay for the patient based on the level and seriousness of his injury. This allows for the calculation of the cost of treatment in terms of hospital fees, service fees as well as lost income for the patient and his family members. Future loss of income after the final outcome of SCI was not considered.

In parallel, a survey among actual persons with SCI and their families was done in order to have their view as “consumers” on which services they are prepared to pay for or would need. The “consumer” view makes them a participant in this exercise. Considerations such as transparency in billing costs, added value services, “luxury items“ were also collected and put into perspective in cost calculation.

The very difficult task of creating a screening system including a questionnaire and criteria for defining the thin line between being entitled or not to support should be seen as a constant changing pattern in the field of health care.

Note needs to be taken that everything has a price and need to be as sustainable as possible. A balanced budget is the target BUT there should be accessible care for the largest proportion of the persons with SCI. Services should not rely on donations.

Based on this concept, precise calculation of cost could be made taking into account ALL costs involved, including direct as well as indirect (from services provided, products delivered and functioning costs as well as depreciation of infrastructure).

Medicines and material for patients makes up almost 45 % of the total functioning cost, staff salaries come second with almost 25 %, trailed by 17 % of depreciation for equipment and building.

Based on the standard of care, the total budget calculation estimated a cost of US$134750 for a 30 bed unit to care for an average of 100 patients per year. This remains still a very theoretical figure.
The principle of an equity fund is to include in every payment made by the patients a percentage destined to a reserve fund to allow for health care for the needier patient. The allocation of this fund money is decided through social screening criteria.

Financing care for SCI people is a very big challenge. Legal enforcement and civil liability for working and traffic environments can support SCI care financially in the long term. Consumer participation and satisfaction around this care should always be sought. Continuing improvement of protocols of care and time management of care should be part of normal functioning of an SCI care setting to adjust financial needs for this care.

Lots of work needs to be done on financing integration costs such as accessible housing, special equipment, small business loans etc.)

5.4.3. What is appropriate technology
The provision of appropriate assistive device technology and products is seen as a major stumbling block in service delivery. Africa is relying heavily on donations and policy makers seem to be unaware of the adverse effect of donation.

Appropriate assistive device technology is a system that provides devices that fits properly and that are based on sound biomechanical principles which suits the needs of the individual and can be sustained by the country at the most economical and affordable price.

The device must be:
- Appropriate to the context.
- Should be easy to maintain, effective and have a wide ‘positive’ impact.
- Affordable and cosmetically acceptable.
- Patient centred.

The ultimate goal of appropriate assistive devices is the:
- Restoration of function and quality of life
- Re-integration of the disabled person into the community
- Enable the disabled person become economically and socially independent

The sentiment was expressed that assistive devices used in Africa often do not comply with the suggested criteria and that Africa needs to continuously strive towards meeting these criteria. In the face of a lack of dedicated assistive devices budgets, Africa seems to be happy to accept second best.

Further reference was made to the GATE document.

GATE [http://www.who.int/phi/implementation/assistive_technology/concept_note.pdf](http://www.who.int/phi/implementation/assistive_technology/concept_note.pdf)

The issue of assistive devices was further explored on day 2. Please refer to section 6.2.4. on page 14.

5.4.4. ASCoN
The Asian Spinal Cord Network (ASCoN) was initiated in 2001 and has 76 member organisations in 18 countries in Asia. ASCoN became an affiliate society of the
International Spinal Cord Society (ISCoS) in 2004. ASCoN consists of a group of organisations in the Asia region that have come together to share and learn from each other in all aspects of SCI management, from initial treatment of the patient to reintegration of the person.

Its objectives are:

- To strengthen SCI services and human resources of organisations working in SCI management in the Asia region.
- To share information, ideas and knowledge of best practices in SCI management among members.

ASCON had an impact on supporting service development, standardising care i.e. CIC. ASCON is an E-learning project partner and gave input into the E-learning and textbook development for regional relevance. It also has a disaster management response component.

The development of Human Resource and technical development of the SCI workforce remains one of the focus areas and achieved through annual conferences; ASCON training centres, technical and human resource development support to new centres, promotion of www.elearnSCI.org, SCI workshops, Regional Fellowship programme and facilitation of international resource persons’ support.

These efforts were richly rewarded and AFSCoN need take cognisance and strive towards achieving the same. The rewards include:

- Creation of a community of practice – a network of people with a common goal, who collaborate together and grow through shared resources and shared training opportunities.
- A high impact low cost model which has united SCI professionals organisations and people with spinal cord injuries across Asia
- Diminished the feeling of isolation experienced by health care professionals/organisations working in the field of SCI management
- Guidelines on Comprehensive Management of SCI
- Guidelines on Prevention of SCI
- And soon to be launched guidelines on Psycho-social management
- Centres that did not exist when ASCoN was born, have become references and training grounds for other countries 14 years later
- Involvement in international projects -www.elearnsci.org and ISCoS textbook

The main ingredients for the success of AFSCoN were:

- Dedicated and enthusiastic members to drive the network
- ASCoN secretary coordinating activities
- Volunteers
- Camaraderie
- Effective partnership working
• Financial contributions from various donors
• Ease of membership registration
• Minimal official/administrative procedures to follow.
• Training opportunities and education of members/health care professionals
• Cross fertilisation of ideas and themes relating to SCI care such as:
  o technical know-how
  o solutions for funding and
  o services design and set-up
• Exchange visits between ASCON countries with modest means.
• Easy discovery and low barrier access to peers within the ASCoN network

ASCoN further suggested to AFSCIN that the strategic plan must be updated regularly at annual conferences and meetings to achieve goals. Lots of hard work and energy will also be needed.

5.4.5. Networks
Currently there are three networks under the ISCOS banner they are:
• For Physiotherapists: SCIPT  
  www.scipt.org
• For Occupational Therapists: SCIOT  
  www.sciot.org
• For nursing: SCINURSE  
  www.scinurse.org
• Soon to come SCIPSYCHO-SOCIAL (for peer counsellors too)

Please visit these websites for more information and note that all three have Face book pages too.
However, for nurses, the network is a non profit initiative created by nurses for nurses and is affiliated with ISCoS. It is aimed at nurses working with men, women and children who have sustained a spinal cord injury and it is free to join.
Some of the main activities have been the creation of a newsletter, running of workshops and conferences on bladder, bowel and skin management, nutrition, respiratory care, sexual function, psychological considerations and autonomic dysreflexia.

6. DAY 2:

6.1. RELEVANCE of AFSCIN
It was felt that in order to proceed with AFSCIN the necessary commitment must be gained from those present. This was done in country specific working groups.
Three questions were posed to each country:
• Is there a need for AFSCIN?
• If yes what should its priorities be?
Would your country be willing to support AFSCIN future plans? Countries broke up in country specific groups and discussed these questions.

In summary all countries indicated that there is a need for AFSCIN and that they were willing to support future activities.

- The need for African solution for African problems
- AFSCIN can be the “torch bearer”
- Consumers and health workers to lobby governments and advocate for funding and resources.
- Assist in policy adjustment and development for example accessibility (i.e. ADA in USA)
- Need for networking between countries and all stakeholder to increase knowledge and finding solutions
- Need to support the development of a centre of excellence in each country and a dedicated team and ward in hospital.
- Professional development and training
- Research and data base development, as well as the funding thereof.
- Need to support the development of standardised care/ protocols / guidelines best practise examples and policies
- Facilitate consumer network and peer counselling
- Suppliers/ technologies not available in some countries and are needed.
- Identify local task force/ work group.
- Prevention effort / activity is needed
- Secondary complications needs to be prevented – leads to high mortality rate.
- Dissemination of information about AFSCIN
- Sustainability of projects and services.
- Sustainable organisations focused on SCI
- Countries to link with ISCOS and establishment of own organisations.
- Special attention to the need of women.
- Care giver education.
- The need for intersectoral support such as the transport system.

6.2. FUTURE PLANS

It was clear from session 1 that people with SCI and other disabilities in Africa continue to face huge challenges in accessing the healthcare and rehabilitative services that they require. It was also apparent that participants felt there was a clear need for AFSCIN to help bridge the gaps that exist. Therefore the next session focused on identifying strategies and specific actions and priorities for AFSCIN going forward.

Participants were divided into six groups and asked to discuss the role of AFSCIN in relation to each of the 6 building blocks of the WHO and ISCOS International Perspectives on Spinal Cord Injury (IPSCI), Chapter 5 that advocates a “Health Systems strengthening” approach. This approach aims to improve the overall performance and responsiveness of the health system and is implemented with consideration to six building blocks. A brief summary from the IPSCI document is provided in Italic, followed by a summary of the group discussion.

6.2.1. Leadership and governance

The Convention on the Rights of Persons with Disabilities (CRPD) states that “all people with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” and that States Parties must undertake appropriate measures to ensure access to health services, including rehabilitation as described in both Article 25 and Article 26 of the Convention.

The brief posed to the group: How to influence policy and guidelines for the development and management of rehabilitation facilities and expected standards for the delivery of comprehensive rehabilitation services. How?

From the discussions the following issues were raised:

- Establish an entry point and establish AFSCIN regional committees
- Built up links with other related organisations such as ISCOS, African Union (AU) and Southern African Development cooperation (SADC)
- Development and strengthening of guidelines of SCI
- Bring countries together to agree on minimum standards.
- Advocate and raise awareness through the media and IEC
- Support and strengthen the development of policies
- AFSCIN can be an engine to mobilise resources and funds.
- Focus and support activities to prevent SCI.
- Research needs to be carried out to enable AFSCIN to lobby, advocate and the subsequently implementation of research.
- Mobilise resources.
- Strengthen with voice of the consumer

6.2.2. Service delivery

Systems for the delivery of health-care and rehabilitation services (including assistive technology) vary throughout the world. In terms of pre-hospital care, several different models exist, ranging from advanced systems of care that utilize highly skilled health personnel to volunteer-based systems that are common in areas where there are few resources. Regardless of what system is in place it is essential that pre-hospital care is integrated into the existing health-care system.

The brief posed to the group: How to support development of comprehensive rehabilitation services (pre-hospital and acute care, post-acute rehabilitation, lifelong care and follow up) that consider the physical, psychological social and economical impact of SCI. How?

- Steps To Comprehensive Rehab Services
  - Pre hospital Care
  - Acute care
  - Post Acute Care
  - Long Term Care
- Pre Hospital Care
  - Prevent Further Damage - Assume SCI unless otherwise proved
  - Public Awareness Campaigns - Media (Radio, TV, Social Media)
  - Involve Government - awareness, policies to communities
o Education; Ambulance professional and ambulance control - what to do/not to do.
o Equipment - appropriate; spinal board, collar etc
o Referral to Main Hospital with Xray facility

- Acute Care
  o Emergency Department
  o ICU/Ward

- Emergency Department
  o Management of patients,
  o Training needed to the stage
  o Staff needed
  o Intervention needed.
  o Family and patient psychological support
  o And referrals

- Post Acute
  o Active rehabilitation once spine is stable
  o Goal planning meetings with patient as focus
  o Peer support
  o Patient and family education
  o Family education
  o Discharge planning - town visit, home visit, patient preparation
  o Lifelong care
  o Outreach visits
  o Community Based Rehabilitation services. (CBR)
  o Out Patient follow up by specialists (SCI, Urologist, Neuro Surgeon)
  o Equipment supply and maintenance
  o Return To Employment

6.2.3. Human resources

People with SCI require access to a wide range of skilled personnel who are able to provide both general and specialist health-care and rehabilitation services. These personnel include medical doctors (e.g. emergency physicians, general practitioners, neurologists, rehabilitation physicians/physiatrists, surgeons, urologists), nurses, paramedics, prosthetists and orthotists, psychologists, rehabilitation engineers, therapists (occupational therapists, physiotherapists, speech therapists), social workers and a variety of support staff, including community-based health and rehabilitation personnel.

The brief posed to the group: Increased knowledge, skills and confidence of staff working in the provision of healthcare and rehabilitation services of Africa. How to support appropriate skill mix and numbers of health care professionals working in the rehabilitation sector?

From the discussions the following issues were raised:

- Strategies needed to increase knowledge, skills and confidence
- For knowledge to improve there must be accessibility to educational material both printed and electronic.
- Skills: establish exchange and site visit to learn from each other
- To build confidence, teaching and sharing are needed, both locally and internationally.
The appropriate skills mix and numbers are needed for doctors, nurses, occupational therapists, physiotherapists, peer councillors, peer supporters, and psychologists.

Ancillary health care workers and assistants needs to be trained to ensure continuity of care.

6.2.4. Health technologies

Health technologies are required across all phases of health care for people with SCIs, and they are essential for safe and effective prevention, diagnosis, treatment and rehabilitation. Health technologies can be broadly categorised under the following areas: emergency and essential surgical care; diagnostics and laboratory technology; diagnostic imaging; and medical devices (including assistive technology). Although also discussed elsewhere, assistive technology and wheelchairs are the particular focus of this section.

The brief posed to the group: How to support increased availability of cost effective and appropriate assistive technology?

Categories of devices identified as needed:

- Mobility Devices
- Orthotic Devices
- Activities of daily living devices
- Ventilator devices
- Incontinence products
- Sexual devices

What is required?

- Accessibility devices standard checklist before discharge in conformity with the client’s needs/environment
- Availability of assistive devices locally
- Development of maintenance services locally
- Patient and care giver training re maintenance
- Standardised training and education of prescribers on all assistive devices

Of note:

- All Devices Are Important
- standardisation of infrastructure for individuals living with a disability
- Donations remain a problem – Involve Government and develop guidelines for appropriate donation of mobility devices in consultation with health care professionals.

Documents available from WHO:

- Launching of WHO Wheelchair Service Training Package for Managers and Stakeholders
  

- Joint position paper on the provision of mobility devices in less resourced settings
  
  [http://apps.who.int/iris/bitstream/10665/44780/1/9789241502887_eng.pdf](http://apps.who.int/iris/bitstream/10665/44780/1/9789241502887_eng.pdf)

- Guidelines on the provision of manual wheelchairs in less-resourced settings
  
  [http://apps.who.int/iris/bitstream/10665/44780/1/9789241502887_eng.pdf](http://apps.who.int/iris/bitstream/10665/44780/1/9789241502887_eng.pdf)
Concept Note: Opening the GATE for Assistive Health Technology: Shifting the paradigm Global cooperation on Assistive Health Technology or GATE, a WHO global initiative.

http://www.who.int/phi/implementation/assistive_technology/concept_note.pdf

6.2.5. Information systems

Many countries lack basic information about SCI. Information about SCI at the individual, service and population levels is imperative to facilitate health sector planning and budgeting, to guide injury prevention and health promotion efforts, to assist with directing further research and to improve outcomes of rehabilitation. Information should be collected at the individual, service and population levels.

The brief posed to the group: How to support information, data collection and research development to facilitate health sector planning and budgeting; to guide injury prevention and health promotion efforts; to assist with directing further research and to improve outcomes of rehabilitation Services?

- ISCoS guides data sets
- Data sets to be made contextual
- Start with Core Set
- Think about ways to collect and collate data
- Outcome measures; use that are applicable to settings such as ASIA scale

AFSCIN ROLE

- What are basic data sets required?
- Recommend data sets to be used
- Forward information to the member countries
- Information collected can influence research,
- AFSCIN to set up standard operating procedures budget and financing
- Does AFSCIN have the resources to manage, maintain and facilitate information?

6.2.6. Financing

People who have sustained SCI require ongoing access to medical care and rehabilitation from the time of injury. Therefore both the initial and ongoing costs associated with SCI can be significant. These costs vary according to the context and type required and cannot be generalized across settings due to differences in health system structures and funding.

People with SCI often face additional health service expenditures and out-of-pocket payments, which can place undue stress on individuals and their families.

The brief posted to the group: How to support mechanisms, to ensure the availability of funds, to strengthen existing and develop new healthcare and rehabilitation services for all (pre-hospital and acute, post cute rehab, health maintenance and long term follow up). How?

ADVOCACY

- Budgets - Government to make budget available
• Locally - Awareness raising
• Regulations - i.e.; exchequer accounts etc
• Consumer - peers to play a role in lobbying for Funding

ACCOUNTABILITY
• Reporting structures
• Grants - NGO
• Government

INSURANCE
• Workers Compensation Act
• Road Traffic Accident Fund (in some countries)
• Private insurance (small population)

NGO/PRIVATE SECTOR GRANTS
• Corporate social responsibility
• Education of companies about SCI is needed i.e. “how to do it” and employ people with a SCI

FUNDING FOR SERVICE DEVELOPMENT
• Establish SCI Service
• Human resources
• Advocacy for economic development - a big issue to address in Africa
• Equity Fund - system HI developed in Vietnam; graded system of ability to pay. Those who could afford could subsidise those who could not pay
• Involvement of media to promote SCI services

TAKE HOME MESSAGE
• Comprehensive - inpatient, outpatient, lifelong care
• Multiple sources
• Cost of disability

6.2.7. Research

Research relating to the medical care and rehabilitation of SCI has taken place for decades and, as a result, there have been many gains that have enabled people with SCI to maintain a high quality of life and to live as long as the general population. Further health service research is required to determine rates of access (19) and to identify cost-efficient and equitable service delivery models for improving access. Evidence based guidelines are also needed by a wide range of stakeholders, including people with SCI, health-care personnel, governments and funding bodies.

This section was discussed as part of section number 6.2.5: Information systems.

6.3. Consumer network

From the onset in planning AFSCIN the involvement of consumers was seen as key to its success. It transpired that in some countries the only rehabilitation services that are available is provided by consumers. During deliberations it became clear that peer support need to be one of the priorities in developing SCI services in Africa. Furthermore, a consumer group was created by consumers present and it will be expanded to other countries. Consumer and peer support need to form the backbone of services delivery.
7. THE WAY FORWARD

In summary from the deliberation, the following strategies need to be developed:

- Raise aware need regarding issues pertaining to SCI by lobbying governments
- Develop a strategy for the establishment of comprehensive service
- Develop data bases and support research initiative to quantify the need.
- Develop minimum standards of care
- Increase skills and knowledge
- Consider various funding models.
- Expanding AFSCIN to more countries in Africa

8. AFSCIN EXECUTIVE

A meeting was convened and a committee formed with representatives from participating countries and country representatives who could not make it due to visa restrictions:

- Representatives
  - Botswana: Tiny Seipone
  - Cameroon: Sister Victorine Ngaibe
  - DR Congo: Georges Meya
  - Madagascar: Rakotonirainy Renaud
  - Malawi: Bylon Kondowe
  - Namibia: Michael Jario
  - South Africa: Elma Burger, François Theron
  - Tanzania: Simon Mallya
  - Zambia: George Sampa/ and Wisdom Katutwa
  - Zimbabwe: Cecilia Nleya

The following was discussed and decided upon:

- Communication will mostly be electronically.
- Elma Burger will chair until the next AFSCIN conference 2017.
- Bank account and auditors will remain with SASCA
- Constitution: At this stage not needed.
- NGO status: AFSCIN does not want to be an NGO but rather collaborate with existing NGO’s.
- Symposium report – Distribute with executive summary as wide as possible.
- Expanding - All delegates to be involved with this.
- Next AFSCIN - will take place Feb/March 2017.
- Involving other organisation’s - International organisations can be invited, including SADC, African CBR network, Motivation, HI, International Red Cross, Whirlwind wheelchairs and any other appropriate entities
- AFSCIN Link with ISCOS and ISCOS Education committee critical.
- Training initiatives should be done and AFSCIN should strive to achieve more that an annual symposium.
- Operational budget to be determined.
SCI Consumer representatives - The formation of an AFSCIN consumer committee was proposed. The consumer committee will be represented on the AFSCIN Executive by Mr Bylon Kondowe from Malawi.

9. DAY 3:

The Symposium concluded with the following clinical orientated talks
Vocational Rehabilitation – Hester Van Biljon South Africa
Medical Care and Complication Management – Dr Ronald Reeves USA
Psycho-Social Care and Relationships - Dr. Stan Duschane USA
SCI Nursing Care – Fiona Stephenson UK
These talks are available on request.

10. CLOSURE AND EVALUATION:

It was envisaged that AFSCIN will only be held every second year. However there was concern that the momentum gained would be lost. It was therefore recommended that AFSCIN 2 be held in March 2017 and will thereafter meet annually in the same period.

It will be the responsibility of the Executive Committee will to take action plans forward and to organise AFSCIN 2. This will include indentifying the host country for AFSCIN 2.

All participants were requested to alert other countries/interested parties to the existence of AFSCIN.

The audience felt that the format for AFSCIN 1 worked well and it was suggested that the format for AFSCIN 2 be based on the same principle i.e. a 2-day workshop followed by a day of clinical training.

The official email for AFSCIN is: afscin@gmail.com

11. CONTRIBUTORS.

A special word of thanks is extended to all suppliers for their generous contribution:
- Chairman Industries www.chairmanind.co.za
- ISCOS www.iscos.org.u
- HiTech Therapy www.httherapy.co.za
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- Rick Hansen Foundation www.rickhansen.com
- SASCA www.sasca.org.za
12. MAP OF COUNTRIES INVOLVED.