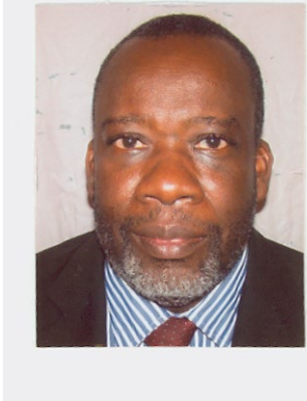


Table of Contents

1. WELCOME MESSAGE FROM THE VICE CHANCELLOR, UNIVERSITY OF MALAWI.....	2
2. WELCOME MESSAGE FROM THE CHAIRPERSON OF ORGANIZING COMMITTEE AND DEAN OF FACULTY OF SOCIAL SCIENCE, CHANCELLOR COLLEGE, UNIVERSITY OF MALAWI	3
3. WELCOME MESSAGE FROM AFRINEAD CHAIRPERSON	4
4. ORGANIZING AND TECHINCAL COMMITTEE.....	5
5. GENERAL INFORMATION	6
6. KEYNOTE ADDRESS SPEAKERS	7
7. AfriNEAD CONFERENCE 2014: OVERVIEW EVENTS.....	17
8. PROGRAMME OF EVENTS FOR BREAKAWAY COMMISSION GROUPS (PARALLEL SESSIONS)	222
9. BOOK OF ABSTRACTS FOR THE AFRINEAD CONFERENCE.....	233
9.1 CHILDREN AND YOUTH WITH DISABILITIES (A)	233
9.2 EDUCATION: EARLY TO TERTIARY (B).....	311
9.3 ECONOMIC EMPOWERMENT (C)	411
9.4 DEVELOPMENT PROCESS IN AFRICA: POVERTY, POLITICS, AND INDIGENOUS KNOWLEDGE SYSTEMS (D)	500
9.5 HEALTH AND HIV&AIDS (E).....	600
9.6 SYSTEMS OF COMMUNITY BASED REHABILITATION (F).....	69
9.7 HOLISTIC WELLNESS: SPORT, RECREATION, SEXUALITY AND SPIRITUALITY (G).....	79
9.8 RESEARCH EVIDENCE AND UTILIZATION (H)	888
10. SPONSORS AND EXHIBITORS	977
11. RECOMMENDATIONS OF THE 3 RD AFRINEAD SMPOSIUM 2011:.....	988

1.Welcome message from the Vice Chancellor, University of Malawi



Dear Delegates

I would like to welcome you all to the 2014 AfriNEAD Symposium which is being hosted by Chancellor College - a constituent college of the University of Malawi, the Ministry of Gender, Children, Disability and Social Welfare, CBM and the Federation of Disability Organizations in Malawi. I am aware that this is the 4th AfriNEAD Symposium and that the first two were held in Capetown in South Africa and the third was in Victoria Falls in Zimbabwe. While a number of Malawians attended the first three symposia, many Malawians working in the disability and related sectors did not manage to go to these conferences mainly because of cost. A number of studies have been implemented in Malawi by the Ministry of Gender, Children, Disability and Social Welfare, Chancellor College and other constituent colleges of the University of Malawi and our collaborators from all over the world, other institutions of higher learning in Malawi and civil society organizations including Disabled Peoples Organizations.

Many innovative interventions are being implemented in Malawi to address the challenges being experienced by persons with disabilities. This conference being held here in Malawi, therefore, provides an opportunity for many of us to attend and learn from each other. We would like to share with all delegates what is being done in Malawi in terms of research and practice while at the same time learn from you. This symposium also comes at an opportune time as the University of Malawi is striving to make tertiary education accessible to persons with various forms of disabilities as recommended in the Convention on the Rights of Persons with Disabilities, the Malawi Disability Act and the University of Malawi Strategic Plan. As has been the case previously the University of Malawi is committed to working with the Ministry of Gender, Children, Disability and Social Welfare and all stakeholders here in Malawi and outside to advance the rights of persons with disabilities and their families through the provision of research evidence which will inform policy and programming. Once again welcome to Malawi. Enjoy the workshop and scenery. All the best in your deliberations.

Prof. John Saka

VICE CHANCELLOR, UNIVERSITY OF MALAWI

2. Welcome message from the Chairperson of Organizing Committee and Dean of Faculty of Social Science, Chancellor College, University of Malawi



Dear Delegates

The 2014 AfriNEAD Symposium at Sun ‘n’ Sand Holiday Resort in Mangochi, Malawi is being hosted by Faculty of Social Science of the University of Malawi, Malawi Ministry of Gender, Children, Disability and Social Welfare, the Federation of Disability Organizations in Malawi (FEDOMA), CBM and the Secretariat of the African Network for Evidence-to-Action in Disability (AfriNEAD) at Stellenbosch University. This symposium aims at building on the previous symposia with the aim of encouraging each other to intensify disability research and practice to achieve the MDGs in Africa. Research in disability is relevant when the research results are translated into practice. This is the main reason why AfriNEAD symposia need to be supported by all.

The Faculty of Social Science at the University of Malawi considers the AfriNEAD symposium as an opportunity for creating and sharing knowledge on disability actions which have been derived from research activities as a response to the needs of Malawi and the region. We are, therefore, grateful to the AfriNEAD Secretariat for entrusting the responsibility of organizing the symposium to us. We look at this more as an opportunity than a responsibility because of our desire to participate in improving the welfare of individuals with disabilities and their families. Holding the symposium in Malawi has also assisted in enabling more Malawians to attend as well as creating awareness about disability and disability research in Malawi. The Faculty of Social Science at the University of Malawi through the Centre for Social Research (CSR) has been involved in a number of studies in disability and is a keen follower of developments in the sector.

I, therefore, extend a warm welcome to all the delegates who are attending the 2014 symposium, especially to our international guests. It is my hope that you will enjoy the presentations and discussions as well as the hospitality from the ever smiling Malawians. It is also our hope that you will never forget this experience.

Levison S. Chiwaula, PhD
Dean of Social Science and Chairperson of Organising Committee
University of Malawi

3. Welcome message from AfriNEAD Chairperson



As we link again with the AfriNEAD family and continue with the journey of exploring how research evidence can be used as a tool to realize the rights of persons with disabilities in Africa, I would like us to draw strength from two African sayings:

Uhambo alugqitywa ngemini enye – You cannot finish a journey in one day and *Ubude abuphangwa* — You cannot hurry to be tall.

These two African sayings are clear reminders to the AfriNEAD family of the need for steady firm feet as we navigate the daily challenges of placing issues of translation of disability research evidence on the map. As we enter this space and connect with the Peoples of Malawi, we at the AfriNEAD Secretariat acknowledge the interdependence or interrelatedness which enhances the opportunities for networking and mutual interdependence. The NCRPD endorses the concept of mutual interdependence and *ubuntu* principles by highlighting the possibilities for a global approach to disability work, paying particular attention to Article 32- addressing International Cooperation:

States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities.

The theme for this conference is: Intensifying disability research and practice to achieve the MDGs in Africa: our experience and aspirations for the future". As the 2015 deadline for the achievement of the Millennium Development Goals (MDGs) draws near, organs such as the UN General Assembly in 2011, the 2013 High-level Meeting on Disability and Development and the international community have a critical opportunity to ensure the inclusion of disability in the emerging post 2015 MDG agenda. We, as the AfriNEAD family - Our experience and aspirations for the future in research Evidence includes the drawing of knowledge and wisdom from the lived experiences of persons with disabilities to guide the way forward for the inclusion of disability issues in the post MDG agenda.

Gubela Mji, PhD

Chairperson: The African Network on Evidence-to-Action in Disability (AfriNEAD)

4. Organizing and Technical Committee

Malawi:

Dr Levison Chiwaula (Chairperson)
Dr Alister Munthali
Mr Elius Chizimba
Ms. Monica Phiri
Dr. Maxton Tsoka
Dr. Elizabeth Kamchedzera
Prof. Wapulumuka Mulwafu
Ms Agnes Mkundiza
Ms Masozi Mwale
Mrs Upile Mwandali

AfriNEAD Secretariat -South Africa:

Dr Gubela Mji (AfriNEAD Chairperson)
Ms Hillary Lane
Nondwe Mlenzana
Lieketseng Ned-Matiwane

Contact Details

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Mrs Monica Phiri: +265994024947

Ms Agnes Mkundiza: +265881087268

Tel: +265 1 524 916

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Steering Committee

Isaac Katopola, Department of Disability and Elderly Affairs, Chairman

Felix Sapala, Department of Disability and Elderly Affairs

Levison Chiwaula, Chancellor College

Monica Jamali, Chancellor College

Alister Munthali, Chancellor College

Ellious Chizimba, Chancellor College

Andrew Kachingwe, CBM

Rachel Kachaje, FEDOMA

Gift Munkhondya Khonje, Treasury

Martha Dzanjalimodzi, Department of Disability and Elderly Affairs

Joyce Kwelepeta, Department of Disability and Elderly Affairs

Patrick Chisamba, Department of Disability and Elderly Affairs

Max S Nyirenda, Department of Disability and Elderly Affairs

Action Amos, Department of Disability and Elderly Affairs

Margaret Wazakili, Department of Disability and Elderly Affairs

Tamala Kabwaza, Department of Disability and Elderly Affairs

5.0 General information

Registration

Registration will commence on Sunday 2nd November 2014 between 2pm and 5pm and then between 7am and 5pm on Monday, 3rd November 2014. Please ensure that you have registered and paid your registration fees.

Pre- Conference workshop – Sunday, 2nd November 2014

A pre- conference workshop on Country Working Groups has been arranged and it will take place on Sunday 2nd November 2014. It will be facilitated by Dr Margie Schneider from University of Capetown, Prof. Charles Wiysonge from Stellenbosch and Prof Arnie H. Eide from SINTEF

Lunches and teas

The organizing committee will provide lunches and teas to all participants at the conference.

Dinners

Each participant will be responsible for his or her dinner on Sunday 2nd November 2014, Tuesday 4th November 2014 and Wednesday 5th November 2014.

Vice Chancellor's Dinner – Monday, 3rd November

The University of Malawi Vice Chancellor's Dinner will take place on Monday, 3rd November 2014 in front of the main restaurant at Sun and Sand Holiday Resort from 7pm to 9pm.

Accommodation

Each participant will be responsible for his or her own accommodation. Preference is that all participants should stay at the venue of the conference.

AfriNEAD Core Group Meeting – Tuesday, 4th November

The Core Group which is the governing structure of AfriNEAD will have its pre – AGM meeting on Tuesday from 6:30pm – 8:30pm. Venue for

this meeting will be announced during plenary on Monday, 3rd November.

Transport

Transport will be available at both international airports namely Chileka in Blantyre and Kamuzu International Airport in Lilongwe from Saturday, 1st November, Sunday, 2nd November and Monday, 3rd November 2014. The organizing committee will also provide transport on Wednesday, 5th November and Thursday, 6th November from the venue of the conference to the airports. Delegates will be required to \$25 for this round trip. Participants who arrive or depart outside the dates stipulated here will be responsible for their own transport.

Information Desk

A registration and information desk will be situated at the reception and it will be open from 2nd November 2014 to Thursday, 6th November 2014.

Punctuality

It will be important for all the delegates to be punctual for the different activities as detailed in this programme. All presenters should stick to the time that has been allocated to them.

Site seeing

Organizers are not responsible for site seeing. These can be arranged privately. The hotel can help you organize sightseeing.

Photographer

An in house photographer will be present to take pictures of the events. Delegates will have their pictures taken but at their own cost.

Post-conference courses

A post conference writing workshop has been arranged and it will take place on Thursday, 6th November 2014. It will be facilitated by Prof. Leslie Swartz from the Department of Psychology at Stellenbosch University.

6. Keynote address speakers



Mussa Chiwaula

Mussa Chiwaula is Malawi's renowned disability activist who was among the founders of the Federation of Disability Organizations in Malawi (FEDOMA) where he worked as Executive Director for 14 years until January 2014. He now heads the Southern Africa Federation of the Disabled (SAFOD) as Director General, which is one of the leading Southern African disability-focused networks engaged in coordination of activities of organizations of disabled persons in the Southern Africa Development Community (SADC) region. During his years of disability activism in Malawi, he was appointed by President Hastings Kamuzu Banda to serve on the MACOHA Board. He also chaired the Malawi Bureau of Standards. He represented the disability sector at the First Constitutional Review Conference during Malawi's transition from a one party to a multiparty system of government; as well as participated in the development of Malawi's Vision 2020. He was also appointed to chair the taskforce that spearheaded the development of the National Policy on the Equalization of Opportunities for Persons with Disabilities in Malawi, and he was in the forefront in successfully lobbying and advocating for the enactment of the Disability Act.

Marguerite Schneider



Dr Marguerite Schneider is a researcher in the field of disability studies, and project manager for the AFFIRM project at the Alan J Flisher Centre for Public Mental Health, University of Cape Town. This is a project including two randomized controlled trials and capacity building in mental health research in sub-Saharan Africa. Dr Schneider has worked primarily in the area of disability studies and social sciences more generally. She has worked in various social science research in South Africa and as a technical officer at the World Health Organization, Geneva, Switzerland. Her early career was in Speech-Language Pathology and Audiology before moving into broader social science research focusing on disability studies. She obtained her PhD at the School of Public Health, University of the Witwatersrand in 2012 - 'The social life of questionnaires: Exploring respondents' understanding and interpretation of disability measures'.

Dr Schneider's publications have been mainly in the area of disability measurement and statistics, social protection and the role of the environment in disability. She is also involved in international projects such as testing disability measures, investigating the accessibility of health care services for people with disabilities, and including disability in social assistance programmes, disability and poverty and monitoring and evaluation of CBR programmes. These are now expanding into the area of mental health.

Dave McComiskey



Dave McComiskey has been with CBM since 1985 and has served several roles before being appointed President and Chief Executive of CBM International in 2013. Most recently he has been the Regional Director of CBM East Africa. Prior to that, he served as the Regional Director for Southern Africa and as Executive Director of CBM Canada.

Leslie Swartz



Leslie Swartz is a Distinguished Professor in the Department of Psychology at Stellenbosch University. A clinical psychologist by training, he has a long-standing interest in disability and mental health issues. His memoir, *Able Bodied: Scenes from a Curious Life* (Zebra Press, 2010), deals with disability issues in southern Africa and was described by the critic Rob Nixon in the USA as follows: “one of the most remarkable memoirs - and one of the most remarkable works of South African literature - I've read in a very long time. Able Bodied is a tour de force.” His most recent book is a co-edited volume on disability and religion in South Africa, *Searching For Dignity* (SunMedia, 2013). He is founding Editor-in-Chief of the *African Journal of Disability*, and an Associate Editor of *Transcultural Psychiatry* and of *International Journal of Disability, Development and Education*. Current work focusses on issues of capacity-building in the context of disability research, lifestyle and physical activity issues for disabled people, and questions of access to health care.

Tecla Mlambo

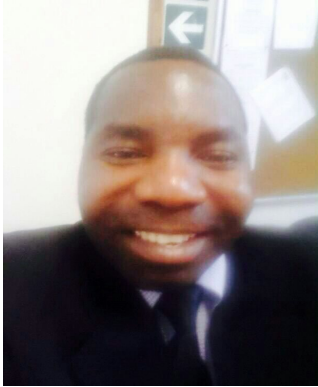


Tecla Mlambo is a lecturer in the Department of Rehabilitation at the University of Zimbabwe College of Health Sciences (UZ-CHS) since 2002. She holds a BSc Honours degree in Occupational Therapy from UZ-CHS, MSc in Occupational Therapy from the University of the Witwatersrand (specializing in neurosciences) and an MSc in Clinical Epidemiology from UZ-CHS. Tecla is currently a PhD student with the University of Zimbabwe College of Health Sciences with sponsorship from Wellcome Trust through the Southern Africa Consortium for Research Excellence (SACORE). Her PhD focuses on neuro-cognitive development in children 6-13 years in Zimbabwe and the impact of HIV. She has received extensive training in areas such as Ethical Issues in Human Research, Good Clinical Practice, Evidence Based Health Care and Intensive Clinical Research. She is the principal investigator for the recently completed wheelchair user satisfaction study in Zimbabwe.

Part of her work involves teaching and supervising both Honours and Masters OT and Physiotherapy students. Her research interests are in child development, neuro-rehabilitation, disability and rehabilitation. She has presented at both national and international fora and chaired the Organizing and Scientific Committees for the 8th Occupational Therapy Africa Regional Group (OTARG) Congress in Harare, Zimbabwe which took place in August 2013.

She is a recipient of the Association of African Universities-Research Publication Network Fellowship (2004), UCSF-OCTAVE/ITAPS Scholarship on Manuscript Writing (2012- 2013), Wellcome Trust/SACORE PhD Fellowship (2012 – 2015), University of Zimbabwe Staff Development Fellowship (1998-2000). Tecla is the current Zimbabwean Delegate to the World Federation of Occupational Therapists (WFOT).

Felix Sapala



Mr. Felix Sapala is the Director of Disability Programmes in the Ministry of Gender, Children, Disability and Social Welfare where he is responsible for coordinating, planning and implementation of disability programmes. He played a critical role in the development of the Disability Act. Previously he has worked as District Commissioner, Director of Planning and Development and District Education Planner. Mr. Sapala is an Economist with qualifications from University of Malawi and University of Bradford.

Margaret Wazakili



Dr. Margaret Wazakili has a wide range of experience working with persons with disabilities. She is the first Joseph P. Kennedy, Jr. International Fellow on Public Policy in Malawi. A major objective of the Kennedy Fellowship is to prepare leaders for work in the public policy arena and to assist government to improve the lives of persons with intellectual disabilities. Dr. Wazakili is an alumnus of the Harvard Kennedy School of Government where she attended a course on Leadership for the 21st Century - Executive Education. Prior to this engagement Dr. Wazakili's Doctoral studies focused on sexuality, disability and HIV/AIDS among young people with physical disabilities at the University of the Western Cape. Then she spent 3 out of her 4 years as a Post-Doctoral Research Fellow at Stellenbosch University, Centre for Rehabilitation Studies, investigating the inclusion of disability in poverty reduction strategies in Malawi and Ethiopia as part of the A-PODD team that worked in Uganda and Sierra Leone as well. She obtained an Internal Diploma in Bioethics at the University of Cape Town. Dr. Wazakili has published book chapters and papers in accredited international journals. She has also taught Physiotherapy students for two years at the College of Medicine as a senior lecturer.

Shona McDonald



Shona started working with children with disabilities after her second daughter was born with cerebral palsy. She has designed numerous unique, and award winning mobility devices, and her company Shonaquip has provided devices together with community based wheelchair seating assessments, fitting and review services to over 70 000 children and training to approximately 450 000 parents, caregivers and health care workers living across all regions of South Africa.

Shona ensures that her social enterprise provides inclusive work opportunities for people with disabilities and through her work with the Department of Health, Department of Social Development and the World Health organization, she continues to influence policy and best practice, developing her business as a real tool for social transformation.

Shona was recently awarded a RESNA honorary fellowship for her commitment to training and mentoring for assistive technology providers, an unwavering advocacy for individuals with disabilities and maximizing health and wellbeing of people with disabilities through her work on appropriate technology.

She holds the World Economic Forum Award for Outstanding Social Entrepreneur - South Africa 2010 and is both an Ashoka and Schwab Fellow

Patrick Devlieger



Patrick Devlieger is professor of anthropology and disability studies at the University of Leuven, Belgium. He is a visiting professor at the University of Illinois, the University of Alberta, and Stellenbosch University. His ethnographic work currently focuses on culture and disability interfaces in Africa and China. Recently, he coordinated a policy oriented research focusing on the perspectives of stakeholders in the implementation of the UNCRPD in Belgium. Publications include '*Rethinking Disability*' of which a second edition is in preparation and '*Blindness and the multi-sensorial city*', and films include 'The Disabling Bullet' and 'Part of the Game'.

7. AfriNEAD CONFERENCE 2014: OVERVIEW EVENTS

PRE-SYMPOSIUM EVENTS

SUNDAY 02 NOVEMBER 2014

- 13:00-17:00 **Country working group-workshop**
Chairperson: Margie Schneider, University of Cape Town
- 14:00-17:00 **Registration begins**
All delegates are encouraged to register and collect their conference bags
- 17:00-18:00 **Chairpersons and Coordinators meeting**
Chairpersons: Gubela Mji, Stellenbosch University and Alister Munthali,
Centre for Social Research

MAIN CONFERENCE PROGRAMME

MONDAY 03 NOVEMBER 2014

- 07:00-08:30 **Registration continues at the reception**
All delegates who have not yet registered to register and collect their conference bags
- 08:30-08:40 **Welcome and Housekeeping**
Chairperson: Alister Munthali, Centre for Social Research
- 08:40-08:50 **Welcome to AfriNEAD Membership**
Speaker: Gubela Mji, Stellenbosch University
- Session1** **Official Opening of the 4th AfriNEAD Symposium**
Chair: Levison Chiwaula, Chancellor College
- 08:50-09:00 Welcome by **Dr. Levison Chiwaula**, Dean of Faculty of Social Science,
Chancellor college
- 09:00-09:15 Welcome by **Antony Muyepa**, Director General, NCST
- 09:15-09:30 Welcome by **Dr. Richard Tambulasi**, Principal, Chancellor college
- 09:30-09:45 Remarks by **Prof Chikte**, Head Department of Interdisciplinary Health
Sciences,

09:45-10:00	Welcome by Prof. Saka Vice Chancellor, University of Malawi
10:00-10:10	Welcome remarks by Honorable Patricia Kaliati , Minister of Gender, Children, Disability and Elderly Affairs
10:10-10:30	Official Opening by Prof. Arthur Peter Mutharika , President of the Republic of Malawi
10:30-11:00	TEA & COFFEE
Session 2	KEYNOTE ADDRESS
	Chair: Elizabeth Kamchedzera, Chancellor College
11:00-11:20	Mussa Chiwaula , SAFOD: <i>A reflection on the SAFOD Research Programme</i>
11:20-11:40	Margie Schneider , UCT: <i>Building Country Working Groups with AfriNEAD</i>
11:40-12:00	Davie McComiskey , President of CBM: <i>A case study of CBM on Building Communities of Trust</i>
12:00-12:20	Gubela Mji , Chairperson of AfriNEAD: <i>A reflection on AfriNEAD on its quest to being an African Disability Research Network</i>
Session 3	ROUNDTABLE DISCUSSION
	Chair: Elizabeth Kamchedzera, Chancellor College
12:20-13:00	Arnie Eide , SINTEF Rachel Kachaje , FEDOMA Theresa Lorenzo , University of Cape Town Action Amos , FEDOMA
13:00-14:00	LUNCH
14:00-18:30	Commission A in Side Room 1 of the Conference Hall Commission B in Side Room 2 of the Conference Hall Commission C in Mcheni Hall Commission D in Mvuu Hall
19:00-21:00	Vice Chancellor's Dinner at the Restaurant

TUESDAY 04 NOVEMBER 2014

08:00-08:10 Brief outline of day's events by **Monica Phiri** from Chancellor College

Session 1 KEYNOTE ADDRESS

Chair: Jessie Chiyamwaka, Ministry of Gender, Children, Disability and Social Welfare

08:15-08:40 **Leslie Swartz**, Stellenbosch University: *Three years of the African Journal of Disability: An Editor's Reflection*

08:40-09:00 **Tecla Mlambo**, University of Zimbabwe: *Wheel Chair User Satisfaction and Function*

09:00-09:20 **Felix Sapala**, Ministry of Gender, Children, Disability and Social Welfare: *A Situation Analysis of Children with Disabilities in Malawi*

09:20-09:30 Questions and responses to keynote address

09:30-10:00 **TEA & COFFEE**

Session 2 FEEDBACK FROM COMMISSION A-D

Chair: Isaac Katopola Ministry of Gender, Children, Disability and Social Welfare

10:00-10:30 **Vivian Duma**, Happy Homes: *Children and Youth with Disability*

10:30-11:00 **Tsitsi Chataika**, University of Zimbabwe: *Education: Early to Tertiary*

11:00-11:30 **Mike Kilonzo** from Kenya: *Economic Empowerment*

11:30-12:00 **Judith van der Veen**, CBM: *Development process in Africa: Poverty, Politics and Indigenous Knowledge systems*

12:00-13:30 **LUNCH**

13:30-18:30 **Commission E** in Side Room 1 of the Conference Hall

Commission F in Side Room 2 of the Conference Hall

Commission G in Mcheni Hall

Commission H in Mvuu Hall

18:30-20:30 **AfriNEAD Core Group Meeting**

WEDNESDAY 05 NOVEMBER 2014

08:00-08:10 Brief Outline of the day's events by **Mr Sapala** from Ministry of Gender, Children, Disability and Social Welfare

Session 1 KEYNOTE ADDRESS

Chair: Action Amos, FEDOMA

08:15-08:25 **Margaret Wazakili**, Ministry of Gender, Children, Disability and Social Welfare: *The International Joseph P. Kennedy Jr. Foundation in Malawi: A qualitative Analysis*

08:25-08:45 **Shona MacDonald**, Shauna-Equip: *Appropriate Wheel Chair provision and Mobility Support Services in South Africa: Outcomes from National Roundtable*

08:45-09:05 **Patrick De Vlieger**, Ku Leiden Belgium: *Coping skills and Development*

09:05-09:30 Questions and responses to keynote addresses

Session 2 BOOK LAUNCH

Chair: Steve Msowoya, Ministry of Gender, Children, Disability and Social Welfare

09:30-09:50 **Roy McConkey**, UCT: *Inclusive Education in Low-Income Countries*

09:50-10:10 **Leslie Swartz**, Stellenbosch University: *Disability and Religion*

10:10-10:30 **Shaun Grech and Karen Soldatic**: *Disability in the Global South: The Critical Handbook*¹

10:30-11:00 **TEA & COFFEE**

Session 3 FEEDBACK FROM COMMISSION E-H

Chairperson: Joshua Mkwehiwa

11:00-11:30 **Margaret Wazakili** from Ministry of Gender, Children, Disability and Social Welfare: *Health and HIV&AIDS*

11:30-12:00 **Nondwe Mlenzana** from UWC: *Systems of Community Based Rehabilitation*

12:00-12:30 **K.C. Khumalo**: *Holistic Wellness: Sport, Recreation, Sexuality and Spirituality*

12:30-13:00 **Leslie Swartz**: from Stellenbosch University: *Research, Evidence and*

¹ This will be done by Prof. Arne H. Eide from SINTEF

Utilization

13:00-14:00	LUNCH
14:00-15:30	Summary of Key Issues by Levison Chiwaula from Chancellor College
15:30-16:30	AGM by all AfriNEAD Network members
16:30-17:30	Network members and Way forward by AfriNEAD Network members
17:30-18:00	Closing remarks

Isaac Katopola, Ministry of Gender, Children, Disability and Social Welfare
Gubela Mji, Stellenbosch University
Dr. Richard Tambulasi, Principal, Chancellor College

END OF SYMPOSIUM

9.0 POST- SYMPOSIUM EVENTS

8:00-10:00	Departure of delegates
9:00-15:00	Research Writing Workshop This aims at refining the writing skills of researchers in readiness for journal publications

8. Programme of Events for Breakaway Commission Groups (Parallel Sessions)

<u>CHILDREN AND YOUTH WITH DISABILITIES (A)</u>	23
<u>EDUCATION: EARLY TO TERTIARY (B)</u>	31
<u>ECONOMIC EMPOWERMENT (C)</u>	41
<u>DEVELOPMENT PROCESS IN AFRICA: POVERTY, POLITICS, AND INDIGENOUS KNOWLEDGE SYSTEMS (D)</u>	50
<u>HEALTH AND HIV&AIDS (E)</u>	60
<u>SYSTEMS OF COMMUNITY BASED REHABILITATION (F)</u>	69
<u>HOLISTIC WELLNESS: SPORT, RECREATION, SEXUALITY AND SPIRITUALITY (G)</u>	79
<u>RESEARCH EVIDENCE AND UTILIZATION (H)</u>	88

9. BOOK OF ABSTRACTS FOR THE AFRINEAD CONFERENCE

COMMISSION A-D: 2nd November 2014. 14:00 - 18:30

9.1 CHILDREN AND YOUTH WITH DISABILITIES (A)

Overall facilitators: Vivian Duma and Judy Mckenzie

SESSION 1: KEYNOTE SESSION

Chair: *Judy Mckenzie*

14:00 – 14:10 Welcome remarks and outline of the programme

14:10 – 14:30 Key note address: *Dickens P. Mahwayo*: The Unmet Needs of Children with Disabilities in Malawi: A close Analysis of Policy and Constitutional Gaps

14:30 - 14:40 Keynote address responses

SESSION 2: NEEDS OF CHILDREN WITH DISABILITIES

Chair: *Nadege Riche*

14:40 – 14:55 *Vivian Vuyelwa Duma*: Challenges Facing Parents of Disabled Children in a Rural Setting in S.Africa

14:55 – 15:10 *Mwawi Kayere*: Children and youth with disabilities

15:10 – 15:25 *Tendai Banda and Alister Munthali*: Barriers to Accessing Healthcare Services for Children with Disabilities in Institutions in Malawi

15:25 – 15:40 *Peter Mvula and Alister Munthali*: Children with Disabilities and Society in Malawi: A Preliminary Audit

15:40 – 15:55 *Ephraim Chimwaza, Patrick Kasauka, Mwai Chaima, Lovemore Amin*: Experience of Youth and Children with Disabilities, their Families and Teachers in Malawi: Excluding in Inclusive Schools

15:55 – 16:10 **Questions and responses to the 5 presentations**

16:10 – 16:20 **Pick up a cup of tea**

SESSION 3: CHILDREN AND YOUTH WITH DISABILITIES

Chair: *Mwawi Kayere*

16:20 – 16:35 *Lameck Saka-Regional Clinician*: Impact of Holistic Approaches for Improving the Lives of Children With Cerebral Palsy (CP) and their Parents/Carers: A Case Study from Uganda

16:35 – 17:50 *Dickens P. Mahwayo*: Investigating the Inclusive Reach, Equity and Access to Basic Services in Addressing Systematic Exclusion Involving Children with Disabilities in Malawi

17:50 – 18:05	<i>Nadège Riche</i> : Perspectives on the Status of the Rights of Children with Disabilities in Uganda
17:05 – 17:20	<i>Malonje Overs Phiri</i> : Working Together: Collaborative Working to Provide Inclusive Education for School Children with Disabilities
17:20 – 17:35	Questions and responses to the 4 presentations
Session 4:	COMMISSION DISCUSSION, RESOLUTIONS, RECOMMENDATIONS & AND WAY FORWARD
Chair:	<i>Vivian Duma</i>
17:35 – 18:00	Feedback & summary of key issues from the presentations - Rapporteurs
18:00 - 18:30	Prioritizing, action plans, resolutions, recommendations & and way forward commission chairs to report the following day

Dickens P. Mahwayo

Dickens holds a Bachelor of Business Administration and a Bachelor of Environmental Science majoring in Climate Change from California South University in the US. He also has certificates in Public Relations and Farm Business Development. He is a Research Director for Given-Secret Foundation and has conducted several studies on systematic exclusion of persons with disabilities including children, climate change versus agriculture, children with disabilities vs. access to public health services and a study on the PWD friendliness of infrastructure development in Malawi versus natural disasters just to mention a few. He has presented papers at both local and international gatherings.

ABSTRACTS IN ORDER OF PRESENTATION

1. The Unmet Needs of Children with Disabilities in Malawi: A Close Analysis of Policy and Constitutional Gaps

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Although it is a general fact that people with disabilities make up to 10 percent of any national population, which simply translates that Malawi has about 1.5 million people with disabilities, there seems to be pockets of laxity in as far as meeting the needs of people with disabilities is concerned, especially the youths and children. The objective of this paper is to uncover evidence based on disability policy gaps which exposes the unmet needs in as far as addressing the plight of people with disabilities in Malawi is concerned. Using this approach, the findings of the paper include the following: The Disability Act of 2012 lacks enforcement elements, general advocacy sensitization drive and accurate interpretation such that those targeted by this piece of legislation, people with disabilities and other users, are not fully aware of its articles. The fact that some national blue print documents and instruments were actually introduced before the Disability Act of 2012, such as the Malawi Growth and Development Strategy (MGDS), Vision 2020; these documents are silent on the plight of people with disabilities, children and youths in particular. The Disability Act on its own lacks clear definition of the strategies through which the challenges affecting people with disabilities can be addressed hence policy monitoring is another challenge. Since the Act and other policies lack a clear enforcement mechanism forcing institutions and groupings to have people with disabilities represented, makes it difficult for these institutions and groupings to come up with policies and principles that address the needs of people with disabilities adequately. In conclusion, just like other policies, the Disability Act of 2012 being a new piece of legislation should be taken to the users for them to identify its gaps and of course appreciate the need for its reform.

Key words: *Disability Act, enforcement, challenges, monitoring, policies*

2. Challenges Facing Parents of Disabled Children in a Rural Setting in South Africa

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The aim of the study was to explore the challenges facing parents of disabled children in rural setting where there are minimal health facilities. The objectives of the study were to describe demographic details of the parents /care-giver of disabled children and describe health related challenges identified by parents/care givers of disabled children. It also aimed at describing how parents/care-givers of disabled children managed and resolved challenges of health and rehabilitation and make recommendations to key stake holders regarding support needed by parents/care-givers of disabled children with regard to health and rehabilitation challenges. As a qualitative descriptive study, participants comprised of parents/care-givers of disabled children residing in a community rural rehabilitation center in the Eastern Cape Province in South Africa. Data was collected from six focus group discussions (FGDs) and one individual interview. Thus a total of 37 participants took part in the study. Data Analysis used a combination of coding and interpretative techniques to determine essential themes. Themes that emerged from the discussions with the parents/caregivers of disabled children in focus group discussions include: challenges with disability diagnosis; negative attitudes of health professionals, health and rehabilitation related problems and lack of support from families and community. The study concluded that caring for disabled children is not easy especially in rural setting where the services are minimal or not available to the neediest people.

Key words: *Disabled children, rehabilitation, health, South Africa*

3. Children and Youth with Disabilities

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There are almost half a million people including both children and adults with disabilities in Malawi. This means that there are a lot of PWD's in Malawi. Most PWD's face a number of challenges in accessing vital information such as family planning and reproductive health due to ignorance or negligence of the service providers, planners or policy makers. There are several long-term actions bringing disabilities issues into overarching government strategy, documents and mainstreaming disability in activities of every child with disabilities can fully enjoy the rights. Figures from 2008 census suggest that the prevalence of disability among children was slightly lower than in the population as whole (2.4% compared with 3.8%). Nevertheless, there are nearly 160,000 children with disabilities in Malawi. Almost 56,000 children had forms of disability categorized as "other"- this includes children with multiple disabilities. More information is urgently needed to flesh out these rough totals, there is no data, for instance on children with intellectual disabilities. Research has shown that most children and youths with disabilities face a lot of challenges in accessing information. This is due to the fact that most vital information is not provided in disability friendly format i.e. sign language and Braille. This exposes this group to a high risk of contracting HIV/AIDS virus and poor family planning practices. There is need for carrying out a comprehensive study on children with disabilities by conducting a national survey. Training more special-needs teachers in order to meet current demand. Children and youth with disabilities have different needs depending on the nature of their disability. For example those who are blind need information to be provided in Braille; the deaf would wish to get information in sign language; albinos and those with low vision need information to be printed in large print and those with physical disabilities want the environment to be accessible.

Key words: *Disabled children, special needs education, HIV, Malawi*

4. Barriers to Accessing Healthcare Services for Children with Disabilities in Institutions in Malawi

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Despite the various conventions on the right to health access, people with disabilities face a lot of challenges in accessing the service in Malawi. This paper explores the challenges that children with disabilities, specifically those in institutions, experience in seeking healthcare. The major objective of this paper is to identify the barriers to accessing healthcare services for children with disabilities in various care institutions in Malawi. Focus group discussions and in-depth interviews were conducted with children in institutions. The findings show that children with disabilities in institutions in Malawi are facing many barriers in accessing healthcare. These barriers include: the lack of money to cater for medical fees and transportation, the lack of appropriate transportation for example for children with epilepsy, the unavailability of or unwillingness of fellow children to escort their friends with visual impairment to health facilities, difficulties in communication between children with hearing impairment and medical personnel and the lack of accessible information for children with visual impairment on health issues. There is a need for these barriers to be addressed so that children with disabilities should be able to access services without any problems.

Key words: disability, disabled children, children in institutions, Malawi

5. Children with Disabilities and Society in Malawi: A Preliminary Audit

Peter Mvula and Alister C. Munthali

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With the paradigm shift in approaches to disability whereby disability is no longer exclusively seen from a medical point of view but also as arising from an interaction between people with a health condition and their environment, the paper explores the interactions between children with disabilities and the society as a whole in Malawi. Using focus groups interviews conducted among children with disabilities and key informant interviews, the papers shows that there is a certain amount of discrimination of children with disabilities in the family, in the community and among peers and therefore strongly advocates for the entrenchment of a human rights perspective dealing with disability issues both in policy and practice. The paper further shows that in the family, disabled children are often times discriminated against when it comes to education, health and other social issues. In terms of gender, the paper shows how, due to their considered vulnerable nature, girls are discriminated against less compared to boys. It is, however, not entirely doom and groom for children with disabilities as there is some sympathy and support from some quarters of the wider society, and more so among their peers especially in learning institutions.

Key words: disability, children, discrimination, gender and peers

6. Impact of Holistic Approaches for Improving the Lives of Children with Cerebral Palsy (CP) and their Parents/Carers: A Case Study from Uganda

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In 2013 Motivation Charitable Trust, in partnership with Health and Community based organizations in four regions in Uganda embarked on a DFID funded programme to contribute to the MDGs by increasing the survival and inclusion of disabled children. The programme concentrates on children with CP considering the lack of services, the high prevalence and complexity of the condition. The objectives include increasing parents' knowledge in managing their children, developing support networks through parent groups and improving access to appropriate mobility devices. Gevinah is the mother of 11 year old Masika who has CP. She is a beneficiary of the project from Western Uganda. The paper is based on a case study of one mother's experience gathered in a face to face interview. Gevinah's story illustrated challenges due to attitudes towards disability, lack of appropriate assistive devices, inaccessible medical care and rehabilitation, and geographic and environmental barriers. Through the project her daughter has received an appropriate wheelchair which has improved her posture and reduced chest infections. Gevinah can participate more freely in community opportunities as her daughter is more mobile. She has been further empowered through her support group and can share and learn from others in similar situations. Training by the trained CBR workers has helped her in numerous ways including enabling her to educate those around her. Her family now understands the causes of CP and epilepsy and Masika is finally accepted into the family. Holistic approaches to supporting families of children with CP improve their lives and empower them to participate in their communities. Working through wheelchair services and CBR groups is an effective way of achieving this.

Key words: *cerebral palsy, disabled children, wheel chairs, Uganda*

7. Investigating the Inclusive Reach, Equity, Equality and Access to Basic Services in Addressing Systematic Exclusion Involving Children with Disabilities in Malawi

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In Malawi and elsewhere in Africa, children and youths with disabilities face pervasive inequality, exclusion and stigma. Though adults with disabilities also face challenges children and youths with disabilities are often denied to enjoy fundamental human rights and access to basic services mainly because they always lack a voice. This paper will elaborate briefly a synthesis of the Situational Analysis (SITAN) of several challenges that children and youths with disabilities are facing in as far as access to basic services is concerned. This was an exploratory, mixed method study conducted between April 2008 and April 2012 to integrate and validate respondents' perspectives towards children with disabilities through snowballing and purposive sampling. Focus group discussions involving children with disability themselves was also conducted. It was found that children and youths with disabilities go through difficult times because of exclusion. Consequently, they live in poverty and hopeless life compared to the general communities. There is lack of sufficient qualified Special Needs teachers in many schools which deny children with disabilities their right to education. Children with disabilities also face challenges as a result of stigmatization and discrimination such that they

cannot participate in sporting, recreational and spiritual activities. There are also pervasive inequalities which disabled children and youths face restricts their capacity, participation and overall human development hence disabled children lack self-efficacy.

Keywords: *disabilities, inequality, challenges, exclusion, participation*

8. Perspectives on the Status of the Rights of Children with Disabilities in Uganda

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In Uganda, the policy context relating to disability is forward looking and rights based, broadly considering the situation of adults with disabilities. However, a lack of knowledge and awareness regarding the status of the rights of children with disabilities (CwDs) has been identified (African Child Policy Forum, 2011). This is also true from the research field where the little information that is available is fragmented. This research aims to explore the situation of the rights of CwDs in Uganda. The study's purpose is to gather and interpret the existing statistical information. It also analyses the extent to which the regulatory and institutional environment enables the realization of CwDs' rights in Uganda. Analysis of the information collected from research conducted on behalf of the United Nations Children's Fund (UNICEF) in Uganda between November 2013 and March 2014, revealed an incomplete understanding of the situation of CwDs' rights in Uganda. Data relating to CwDs are scarce and unreliable. The analysis of the legal and policy framework shows that Uganda has broadly domesticated both the CRC and CRPD but faces challenges in implementing disability policies and services. Although the institutional framework to protect CwDs' rights has been established, weak coordination mechanisms between Government Institutions results in a fragmentation of efforts. UNICEF Uganda is therefore advised to internally mainstream the CwDs' perspective and to partner with government and non-government organizations in view of leading a coordinated programmatic approach answering the needs of CwDs.

Key words: *Children with disabilities; CRC; CRPD, legislation; statistics; Uganda; UNICEF*

9. Working Together: Collaborative Working to Provide Inclusive Education for School Children with Disabilities

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This paper investigates the quality of public service provision for school children with disabilities and their families, in particular, evaluating the role of partnership working in a wide range of local inclusive education projects in Mchinji district, supported by the World Bank. In addition, it explores a possible basic model of information sharing and suggests how information sharing may be influenced by a number of factors. Based on a review of the current literature (Davis, 2011; Roaf, 2002; Ridell & Tett, 2001), this article examines ways in which local partners might influence project delivery and improve school attendance by children with disabilities. Through a series of interviews, the experiences of specialist and regular teachers, other public service providers, such as the Malawi Council for the Handicapped, Social Welfare and health services, the police Victim Support Units and village communities engaged in the project work, are explored. Important issues are raised about collaborative working in public service provision for school children with disabilities which should be open to broader debate.

Key words: *Disabled Inclusive Collaborative Working*

9.2 EDUCATION: EARLY TO TERTIARY (B)

Overall facilitator: Tsitsi Chataika and Anthony Edusei

SESSION 1: KEYNOTE SESSION

Chair: *Anthony Edusei*

14:00 – 14:10 Welcome remarks and outline of the programme

14:10 – 14:30 **Key note address:** *Jill Hanass-Hancock and Leandri Pretorius*: “I have come out of my Shell”: Enabling teachers to effectively deliver sexuality education to learners with disabilities

14:30 - 14:40 Keynote responses

SESSION 2: PRE-SCHOOL TO SECONDARY EDUCATION

Chair: *Angstone N.J. Thembachako Mlangeni*

14:40 – 14:55 *Roy McConkey and Lilian Mariga*: Implementing Inclusive Education in Africa

14:55 – 15:10 *Christopher Mtalimanja*: An Investigation of Educational Support Programmes for Learners with Acquired Deaf Blindness in Secondary Schools: A case of Stella Maris, St. Patricks and Thyolo Secondary Schools

15:10 – 15:25 *Ida Mbendera and Stella Kalengamaliro*: Impact of hidden cost of free primary education on Inclusiveness

15:25 – 15:40 *Tsitsi Chataika and David Chakuchichi*: Promoting Article 24 of the United Nations Convention on The Rights of Persons with Disabilities in Zimbabwean Primary Schools

15:40 – 15:55 *Elizabeth T. Kamchedzera*: Teachers’ Experience in Implementing Inclusive Education in Malawi’s Inclusive Secondary Schools

15:55 – 16:10 **Questions and responses to the 5 presentations**

16:10 – 16:20 **Picking-up a cup of tea**

SESSION 3: TERTIARY TO WORK

Chair: *Roy McConkey*

16:20 – 16:35 *Anthony Kwaku Edusei and Dahamani Tahidu*: Attitude of Teacher Trainees towards Pupils With Disabilities in the Nanumba North and South Districts of Northern Ghana

16:35 – 16:50 *Heidi Lourens*: Special, Inclusive and Higher Education: A Retrospective Glance

16:50 – 17:05 *Hanneck Mdoka*: What causes Children/Youth with Disabilities to Drop out of School in Malawi?

17:05-17:20 *Aurélien Daydé*: Making the data revolution real-the power of numbers for post -2015 Indicators and persons with disabilities in Africa: how to improve the monitoring of Employment and education policies in Zambia and Malawi

17:20-17:35 *Kenneth Kapalu Muzata*: Making Educational Assessment Inclusive for Learners with Learning Disabilities

17:35-17:50	Angstone N.J. Thembachako Mlangeni: Comparison of homework submission defaults Levels Among students operating from own home, self-boarding and full boarding facilities
17:50 – 18:10	Questions and responses to the 5 presentations
SESSION 4:	COMMISSION DISCUSSION, RESOLUTIONS, RECOMMENDATIONS & AND WAY FORWARD
Chair:	<i>Tsitsi Chataika</i>
18:10– 18:15	Feedback &summary of key issues from the presentations - Rapporteurs
18:15 - 18:30	Prioritizing, action plans, resolutions, recommendations & and way forward commission chairs to report the following day

Jill Hanass-Hancock



Is a Senior Research Specialist at Health Economics and HIV and AIDS Research Division (HEARD) disability research program. She completed her PhD on the vulnerability of people with disabilities to HIV in South Africa in 2008 and was awarded a magna cum laude from the Humboldt University in Berlin. Since 2008 she has been working at the HEARD at the University of KwaZulu-Natal. In recent years she has been involved in the evaluation of an HIV & sexuality education community programme in KwaZulu-Natal and several studies on the intersection of disability and HIV. She has developed HEARD's disability research programme which focuses on the vulnerability of people with disabilities to HIV as well as HIV-related disability. Sexual violence is a recurring issue in particular for girls and women with disabilities and research indicates that a lack of comprehensive sexuality education and disability community sensitization are drivers of this increased vulnerability. Hence Dr. Hanass Hancock conducted in HEARDs disability programme several needs assessments as well as developed, piloted and evaluated several tailored interventions. Most recently she has conducted a needs assessment with teachers of learners with disabilities in regards to sexuality education. Based on this assessment she developed and piloted a tailored intervention including a curriculum innovation. This study has been conducted in cooperation with the KZN department of education and Disabled Peoples Organizations and is currently undergoing formative evaluation. Dr. Hanass-Hancock brings also unique skills to this project has worked for many years as a teacher and educational psychologist before pursuing an academic direction. She has many years of experiences as an educator as well as researcher. Dr. Jill Hanass-Hancock has 8 years of educational training (BA/MA and internship) as well as almost 10 years of experiences as an educator of various groups of pupils, including the provision of sexuality education. She has taught learners of different ages (in particular adolescents) in three different countries (Germany, England and South Africa) and has specific expertise for learners with disabilities.

ABSTRACTS IN ORDER OF PRESENTATION

1. “I have come out of my shell”: Enabling teachers to effectively deliver sexuality education to learners with disabilities”

Jill Hanass-Hancock, Leandri Pretorius

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Young people with disabilities are at increased risk of exposure to HIV because they have less access to HIV information and education, are more likely to be a victim of sexual violence and are more likely to live in poverty with less access to healthcare. Sexuality education is important in overcoming this vulnerability. Teachers in South Africa lack the skills and tools to accommodate learners with disabilities when discussing sexuality and HIV and struggle with conflicting cultural values. A needs assessment was conducted which provided the basis for the development of an intervention enabling teachers to provide sexuality education. This study presents the results from the formative evaluation process. A mixed-method approach was used including an assessment of the teachers’ knowledge, attitude and practice, a pre- and post-workshop evaluation, an audience analysis and self-administered observation notes made during the workshop. The participants were purposely selected by the Department of Education. Quantitative and qualitative methods assessed their experiences after the workshop. The 98 participants identified numerous barriers to teaching sexuality education to their learners: perceived resistance from the parents, uncertainty about when to teach what and that some topics might encourage sexual activity. Teachers expressed concern about dealing with inappropriate sexual behaviour and sexual abuse. The post-workshop evaluation indicated that teachers felt empowered to take their new knowledge and skills back into their schools. Preliminary results indicate that the *Breaking the Silence* approach is effective in equipping teachers with the skills and knowledge to provide sexuality education. Teachers need support, so this intervention needs to be embedded into a whole-school approach including intense parent work.

Key words: *Sexuality education, learners with disabilities, KwaZulu-Natal*

2. Implementing Inclusive Education in Africa

Roy McConkey and Lilian Mariga

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In Africa the only feasible strategy of ensuring that children with disabilities receive the right to education is through inclusive schooling. Yet this has proved especially challenging given the large enrolments and scarce resources within the education systems in most African nations. Based on experiences in Lesotho, Tanzania and Zanzibar, a community-based approach to inclusive schooling has developed based around partnerships such as multidisciplinary working among professionals, creating awareness within families and the wider community as well as soliciting the support of other service sectors. However the implementing of such approaches locally and nationally is not easy. This paper describes an illustrated workbook, supported by specially made video programmes, that aims to educate local schools and communities about inclusive

education through giving information, sharing skills and changing attitudes. The resources are freely available from the Internet². The workbook is presented in three parts: Introducing Inclusive Education; Promoting Inclusion and Creating Inclusive. In each section, the content is presented in the form of suggested training strategies for communicating the main themes to the intended trainees and how they might be adapted for particular groups such as teachers, parents and community personnel. Many practical examples are given of strategies that have proved successful in urban townships through to rural communities. In addition to the videos, easy-to-obtain print and audio-visual materials are also identified for use in training sessions. An unresolved issue is who to take responsibility for educating communities about inclusive education. A cross-agency partnership approach would appear most sensible but these are not easy to instigate or maintain. Future research needs to address this and similar issues if future Millennium Development Goals relating to education are to be met.

Key Words: *Inclusive education; community based; training resources.*

3. An Investigation of Educational Support Programmes for Learners with Acquired Deaf Blindness in Secondary Schools: A Case of Stella Maris, Blantyre, St. Patricks and Thyolo Secondary Schools

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Education is a fundamental human right that must be enjoyed by all learners at all levels of education including those with deaf blindness. One of the EFA goals is that education should be provided to all learners regardless of their differences. EMIS (2010) indicates that there are special needs education services being provided to learners with VI, HI and LD in secondary schools. However, it does not show the educational support programmes for learners with deaf blindness in secondary schools. This survey examined the educational support services for learners with acquired deaf blindness in secondary schools. The study data was presented using charts and tables, and was analysed using thematic data analysis and coding methods in spreadsheets. The results found that some support services for learners with acquired deaf blindness, such as large prints, orientation and mobility, sign language, referral were available while other services such as assistive devices, specialist teachers for the deaf blind, one to one teaching, and remedial lessons were not available. The academic success of learners with acquired deaf blindness requires meaningful interactive teaching and learning methodologies.

Key words: *educational support programs, deaf blindness, Special Needs Education, teaching methodologies.*

4. Impact of Hidden Cost of Free Primary Education on Inclusiveness

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The Free Primary Education in Malawi forms the bedrock on which all human capital development for the next twenty to thirty years ultimately

² Copies of the workbook can be downloaded free of charge at: <http://www.eenet.org.uk/>. Videos are available through YouTube: search term: ZAPDD

rests. However, questions have been raised about whether or not the so called free primary education is indeed free and therefore inclusive and equitable as claimed. The prima facie argument is that public primary education is free and therefore accessible to all primary school going children including those from vulnerable groups such as the poor and the disabled among others. This paper is therefore based on a study whose objective was to find out to what extent the free public primary education is “free” for those who attend; and what impact the hidden costs of free primary education have on inclusiveness of public education in Malawi. The study adopted several data gathering methods including a quantitative survey of parents and guardians; qualitative interviews amongst key stakeholders such as members of School Management Committees (SMCs), policy makers, Primary Education Advisors (PEAs) and head teachers in four education districts in Malawi; and examination of key secondary documents. The study found that parents and guardians pay up to 30% or more of the total cost of free primary school education of their wards. Such costs cover for expenses for essential items that have been recommended as necessary for all pupils in order to attain quality education. The study also found that as a result of such hidden costs many vulnerable children including the poor and disabled drop out of school.

Key words: Free primary education, inclusive education, Malawi

5. Promoting Article 24 of the United Nations Convention on the Rights of Persons with Disabilities in Zimbabwean Primary Schools

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In an attempt to re-align the Zimbabwean education system to the Convention on the Rights of Persons with Disabilities (Article 24), Lenard Cheshire Disability Zimbabwe Trust initiated a three-year ‘Schools for All-Inclusive Education’ project in twenty-one primary schools in four provinces. To promote sustainable inclusive education practices, the project, which started in 2010, focused on four broad areas in its implementation strategy. These were increasing disability and inclusive education awareness; improving physical structural access to school amenities, community buy-in and involvement; and capacity building. This presentation is based on the findings of an in-depth evaluation we conducted on this project. School heads, teachers, pupils with and without disabilities and parents took part in-depth interviews and focus group discussions. In addition, we designed an observation check-list for inclusive infrastructure adaptation and social interaction. Despite a few reported challenges, the disability and inclusive education awareness campaigns registered success as evidenced by the general acceptance and accommodation of children with disabilities, the increased enrolments of both children with and without disabilities and enhanced images of the respective schools. Recommendations were made for policy and practice. These included the need for capacity development among teachers in order to ensure improved learning outcomes. We also recommended the need for Lenard Cheshire Disability Zimbabwe Trust, in liaison with the Ministry of Primary and Secondary Education to closely monitor infrastructural adjustments in some schools for them to meet inter/national standards. Overall, it was clear that the selected schools made significant efforts in fulfilling Article 24 of the United Nations Convention on the Rights of Persons with Disabilities.

Key words: *inclusive education; Zimbabwe, Article 24 of the CRPD; children with disabilities; Lenard Cheshire Disability*

6. Teachers' Experiences in Implementing Inclusive Education in Malawi's Inclusive Secondary Schools

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Malawi is party to a number of international human-rights standards and frameworks that embrace the goals and values of inclusion and education for all. The country has therefore made promising start with inclusive education (IE) in basic and secondary education. The purpose of this study was to explore the experiences of teachers in implementing IE in Malawi's inclusive secondary schools. This study will help fill the research gap in understanding the daily lived experiences of teachers in implementing IE. The study adopted qualitative methodology to answer the research questions. The sample comprised of teachers and learners in selected schools in the three regions of Malawi. Purposive sampling was done to identify participants. Data were gathered through questionnaires with open-ended questions and classroom observations. Glasser's (1998) concept of an individual's quality world was used as the analytical framework. Data were analysed thematically. The findings revealed that teachers strongly linked their positive experiences with the learners' eagerness to learn, interest in learning and hard-working nature, and their own professional and technical development. Others found their positive experiences when they gained the knowledge and skills of handling the learners with disabilities. Many indicated that their positive experiences were when their learners with disability did well. The sources of negative experiences for some teachers largely pertained to the learners' difficult or within learning attributes, such as slow learning and lacking the means to deliver IE, and frustration in not knowing how to work with some learners with disabilities. The classroom observations shed more light on the implementation of IE. There was, in general, a common style in the delivery of the lessons in the inclusive classrooms. However, although the common style exemplified general competency and skills in lesson delivery, there was no consistent style to respond to the specific needs of learners with disabilities. In conclusion, teachers' experiences in the delivery of IE should inform policy and practice because they have a rich and diverse source of knowledge about the current practices, issues and challenges.

Key words: *Inclusive secondary schools, disability, inclusive education, teachers' experiences*

7. Attitude of Teacher Trainees Towards Pupils with Disabilities in the Nankumbi North and South Districts of Northern Ghana

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The policy change to promote inclusive education in Ghana has warranted the training of teachers with the relevant skills and attitude to meet the needs of children with special educational needs. Subsequently, Special Needs Education as a course has been introduced in the curriculum of the Colleges of Education. The study assessed the attitude of Teacher Trainees of E.P college of Education, Bimbilla towards pupils with disabilities in two districts in the Northern Region, Ghana, to ascertain the usefulness and relevance of the new course. A descriptive survey design, using a total of 150 teacher trainees selected by stratified random sampling technique out of 285 trainees in their last year in the college of education was employed. A set of questionnaire with items rated on the Likert scale was used to assess the attitudes of teacher trainees towards pupils with disabilities at the Basic schools. Independent sample t-test was used to test gender disparity in attitudes. The findings revealed that, there was no significant gender difference ($p>0.05$) in teacher trainee's attitude towards pupils with disabilities. Positive attitude of the teacher trainees towards

pupils with disabilities, implying that the new course has a potential of producing teachers with the right attitude to teach such children was also revealed. The new course appears useful because all the teacher trainees have positive attitude towards the children with special educational needs. The study recommends that while seminars and workshops should be organized for teachers who did not go through the Special Needs Education course, the teacher trainees who go through the new course should also experience inclusive education during their teaching practice in order to be prepared for the teaching of children with special needs.

Key words: *Children with special needs; teacher trainees; attitude*

8. Special, Inclusive and Higher Education – A Retrospective Glance

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Since the late 1980s, a growing number of disability scholars started arguing for inclusive education for all. The democratic government of South Africa explicitly supported this move towards inclusion, as indicated through various policy developments. However, some scholars have warned that inclusive education requires major societal changes. The aim of the study was to explore the lived experiences of students with a visual impairment at two South African universities. Data were collected through individual and focus group interviews and analysed within the phenomenological, embodied theory of dys-appearance. Findings show that both students from special schools and mainstream schools experienced dys-appearance, either as a result of social rejection in the mainstream, or because their capabilities exceeded the expectations of the environment of a special school. However, in their transition to higher education, these two sets of learners had differing experiences. It seems like students from special schools made friends more easily than those coming from mainstream schools. Further, students from a special school were more likely to ask for reasonable adjustments than their mainstream counterparts. In conclusion, the study makes two suggestions; one is that mainstream schools are not quite ready to accommodate disabled learners and prepare them for tertiary environments, and two, that South Africa has failed in the adequate inclusion of disabled learners; leaving them ill-prepared for tertiary environments.

Key words: *special education, inclusive education, higher education, dys-appearance*

9. What Causes Children/Youth with Disabilities to Drop out of School in Malawi?

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The dropout rate for students with disabilities in Malawi is approximately twice that of general education of other students. Increased concerns about the dropout problem are now emerging. The objective of this study was to critically review and evaluate the factors that influence children and youth with disabilities to drop out of school among several initiatives that mobilize them to get back to school. The study used Action Research methodology and targeting one school in Mangochi where Parents of Disabled Children Association of Malawi (PODCAM) is implementing an inclusive education project. The research targeted a number of stakeholders. The research used observation and interviews to identify areas that make children/youth with disabilities not to perform comparatively well in schools and eventually drop out. Key findings of

the study include, first, that increasingly high-stakes tests have significant consequences for learners with disabilities —they determine whether they are promoted from one grade to the next. Second, the school environment and attitudes are not ready to promote inclusive education but rather integrated education. Third, some of the teaching and learning materials are not inclusive. In conclusion, it is expected that the dropout rate will be reduced if learners with disabilities are appropriately engaged in school with requisite learning materials and environment and that they will successfully complete school with the academic and social skills they need to be successful adults.

Key words: *special needs education, children with disabilities, dropping out of school*

10. Making the data revolution real - the power of numbers for Post-2015 indicators and persons with disabilities in Africa: how to improve the monitoring of employment and education policies in Zambia and Malawi

By Aurélien Daydé

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Although disability is excluded from the current MDGs framework, there is now increasing pledges to make international cooperation inclusive of persons with disabilities. This applied research intends to bring together key DPOs and academics involved in disability and the post-2015 agenda in Zambia and Malawi to include consistent indicators and data for the implementation of the next development agenda in the light of the CRPD. The project seeks to compare and analyze the current indicators used to measure employment and education policies for persons with disabilities in Zambia and Malawi. Good practices from Europe and South Africa will be used to stimulate reflection in order to provide a set of recommendations. A conceptual model and targeted guidelines will be produced in a tool-kit to show what improvements can be offered in an inclusive data collection process. It is intended to take into account a cross disability perspective, covering most impairment, barriers and the family support, including sensorial, physical and psychosocial disabilities. The project is designed so that its conclusions will be widely disseminated in the DPOs, academics and international advocacy networks with the idea of ensuring sustainability and transferability of the methodology where relevant.

Keywords: *Persons with disabilities; inclusion; indicators; data; CRPD; MDGs; Post-2015; employment, education; DPOs; academics*

11. Making Educational Assessment Inclusive for Learners with Learning Disabilities

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This article examines the assessment practices used in the Zambian education system. It explores the nature of assessment used in schools and by the Examination Council of Zambia. The paper identifies the weaknesses in the use of educational assessment especially with particular reference to the Learners with Learning Disabilities. While Colleges and Universities consider learning disabilities as a category among the traditional disabilities, the key education documents (Education policies and curriculum framework) do not. The Examinations Council of Zambia seems to agree with the main education documents. The Council's traditional manner of examining compels learners to take an examination through writing, let alone the braille provision for learners with visual impairments. Examinations are printed and expected to be read and written by all

learners. How much this form of assessment helps learners with learning disabilities is a serious matter of debate in this paper. The paper endeavors to create an understanding of educational assessment in the context of disabilities and proposes options for an inclusive assessment approach to cater for all learners with varying needs including those with learning disabilities. It argues that in the presence of a competency based curriculum, assessment should be more flexible and diverse to embrace technology and assess all learners without discrimination.

Key Words: Educational Assessment, Inclusive Assessment, Learning Disabilities, Examinations

12. Comparison of homework submission default levels among students operating from own home, self-boarding and full boarding facilities

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The study was conducted to determine implications of operating from full-boarding hostels, self-boarding hostels and one's own home on submission and performance of homework in rural community day secondary schools in Malawi. Data regarding girls' performance and submission of homework was obtained from school teachers' records and focus group discussions with community day school teachers. Results indicated that defaulting submission of homework and submission of poorly worked out homework positively correlated with girls operating from own home and self-boarding facilities respectively. Submission of thoroughly worked out homework positively correlated to girls operating from full boarding hostels ($p=0.15$; $\alpha=0.05$). Majority of girls operating from own home (78%) attributed default of homework submission to unavailability of partners to work with and lack of adequate time for homework. Increased burden and anxiety of preparing own meals (92%), lack of supervised studies periods (76%), and unlimited freedom girls operating from self-boarding hostels (88.5%) negatively affected girls' performance and submission of homework. Girls' submission of thoroughly worked out homework and excellent performance positively correlated to team work frequency (87%, $p=0.230$, $\alpha=0.05$) patronage to supervised compulsory studies (99%, $p=0.540$, $\alpha=0.05$), provision of standard meals (76, $p=0.251$, $\alpha=0.05$), and available qualified teachers for consultation (65%, $p=0.250$, $\alpha=0.05$). Governments should consider constructing full boarding facilities in community day secondary school to effective

Key words: *Full-boarding, self-boarding, performance, house chores, community day secondary schools.*

9.3 ECONOMIC EMPOWERMENT (C)

Overall facilitator: Mike Kilonzo

SESSION 1: KEYNOTE SESSION

Chair: *Arnie Eide*

14:00 – 14:10 Welcome remarks and outline of the programme

14:10 – 14:30 Key note address: *Yunusu Dickson*: Inclusive Microfinance and Sustainable Livelihood Pilot Project for Persons with Disabilities in Malawi

14:30 - 14:40 Keynote responses

Session 2: Economic Empowerment

Chair: *Cathy Musola Kaseketi*

14:40 – 14:55 Hellena Makura: A practice based review to demonstrate the importance of locally Manufactured/Available wheelchairs in Southern Africa

14:55 – 15:10 *Diane Bell and Anlia Pretorius*: Transition from University to the workplace: Experiences of Early- Career Graduates with hearing Impairment

15:10 – 15:25 *Gowokani Chirwa, Alister Munthali, Arnie Eide, Hasheen Mannan, Mutamad Amin, Leslie Swartz, Peter Mvula, Levison Chiwaula and Mac Maclachlan*: Socio economic factors associated with labour force participation in Selected African Countries

15:25 – 15:40 *Arnie H Eide*: Access to Assistive Technology in Southern Africa

15:40 – 15:55 *Yanga Terresa Futshane*: An Exploration of Employment Experience of Students with Disabilities Who have studied at UKZN

15:55 – 16:10 **Questions and responses to the 5 presenters**

16:10 – 16:20 **Picking-up a cup of tea**

Session 3: Empowerment

Chair: *Yunusu Dickson*

16:20 – 16:35 *Gwemende Margaret, Mutseekwa Christopher and Matorevhu Alois*: The Student Teacher with Visual Impairment: Perceptions from Stakeholders

16:35 – 16:50 *Myroslava Tataryn , Linda Chokhotho, Wakisa Mulwafu and Petros Kayange*: Epidemiological Assessment of Childhood Disability in Two Districts in Malawi: Using the Key Informant method

16:50-17:05 *Cathy Musola Kaseketi and Julie Schurgers*: Getting the full picture

17:05-17:20 *Colleen Howell*: Exploring how students completing the Post-Graduate Diploma in Disability Studies at the University of

Cape Town *understood* made meaning of the experience of disability in Africa.

Questions and responses to the 3 presenters

Session 4:

COMMISSION DISCUSSION, RESOLUTIONS, RECOMMENDATIONS & AND WAY FORWARD

Chair:

Mike Kilonzo

17:20-17:50

Feedback & summary of key issues from the presentations - Rapporteurs

17:50 - 18:20

Prioritizing, action plans, resolutions, recommendations & and way forward commission chairs to report the following day

Yunusu Dickson



Yunusu Dickson is a professional microfinance manager. He has 9 years' experience in microfinance and has been practicing conventional microfinance with different institutions. He has a Bachelor's degree in Business Administration specializing in marketing from Zanzibar University in Tanzania. He worked with Pride Malawi dealing with microfinance issues as a mere officer, Officer In charge and later rose to a Regional Manager for the northern region of Malawi. He then secured another job with CUMO Microfinance Limited where he worked for 4 years as a Business Area Supervisor. He is now with MACOHA since 2013 coordinating the Inclusive Microfinance & Sustainable Livelihood (IMFSL) pilot project funded by CBM.

ABSTRACTS IN ORDER OF PRESENTATION

1. Inclusive Microfinance and Sustainable Livelihood Pilot Project for Persons with Disabilities in Malawi

Yunusu Dickson

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This paper discusses the preliminary findings from the pilot project under implementation in Malawi where MACOHA and FEDOMA with a concerted effort of CBM are advocating for inclusion of Persons with Disabilities in Mainstream Microfinance Services. The objective is to reduce poverty levels of Persons with Disabilities participating in the project but specifically increase opportunities for sustainable livelihood. The project has partnered with CUMO Microfinance limited in Salima rural and Opportunity Bank in Blantyre urban to provide Inclusive Microfinance access to Persons with Disabilities. The project's result areas are improved income levels and savings culture, increased awareness on disability inclusion by Malawi Microfinance Network (MAMN) members, increased participation of Persons with Disabilities in livelihood related community economic activities and documenting practice knowledge and evidence gained from the project. At the time of conducting this study, the project had an increased number of Persons with Disabilities taking part in Microfinance and other community economic activities.

Key words: *microfinance, sustainable livelihoods, persons with disabilities*

2. A Practice based review to demonstrate the importance of locally manufactured/available wheelchairs in Southern Africa

Hellena Makura, Occupational Therapist/Seating Practitioner, Shonaquip, South Africa

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Wheelchair users from low income earning families who cannot afford to purchase their own wheelchairs are the majority of donor funded beneficiaries of imported wheelchairs by non-governmental organisations. Most of these donated wheelchairs are often inappropriate for the recipients but are regarded as a relief in an environment where the governments or medical aids are not willing to fund wheelchairs for people with disabilities. Donated wheelchair users are ending up with secondary complications such as scoliosis, pressure sores and postural deviations from incorrect seating. Three clients who are wheelchair users were reviewed over a period of two years. First client's wheelchair was donated and imported, second client's wheelchair was donated but locally sourced and the third had privately imported their wheelchair. Clients' and their family were interviewed to find out how the wheelchair they were using was influencing level of participation in daily activities, well-being and self-esteem. Clients with imported wheelchairs struggled to find spares for basic maintenance and repairs. Product specific knowledge of the wheelchairs was lacking resulting in misuse of the devices leading to secondary complications. High medical care from hospitalisations due to secondary complications was common. Short term solution for clients included making low cost wheelchair adaptations to improve sitting posture. A detailed report of problems being faced by the clients as a result of incorrect seating was sent to the funder and clinical team. The funder and families were encouraged in the future to procure a locally manufactured device that would be fitted appropriately. Appropriate wheelchair awareness raising presentations were done for the funders. Training in wheelchair seating and product

specific knowledge was proposed for local rehabilitation personnel and technicians.

Key words: *Wheelchair, local production, persons with disabilities*

3. Transition from University to the workplace: experiences of early-career graduates with a hearing impairment

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Although growing numbers of students with hearing impairment are successfully graduating from South African universities, many of them remain unemployed and those that do find gainful employment are faced with many unexpected challenges. This research study was born because of the absence of research on the personal experiences of graduates transitioning into the world of work in South Africa, especially those with a hearing impairment which is known to be one of the more complex disabilities to support. The main aim of this case study was to explore the barriers to employment, the challenges faced in the workplace as well as the critical success factors – all in an effort to learn about possible changes that can be created in organizations and thereby encouraging the economic empowerment of these graduates with hearing impairment. The study focuses on identity, workplace barriers, coping strategies, reasonable accommodations, organisational culture and support and the major findings will be presented. The methodological approach used for this study was qualitative, making use of an interpretative paradigm. Purposeful sampling led to the selection of information-rich cases in order to gain insight from the authentic experiences of the graduates. The context of the case was two universities in South Africa (one based in the Western Cape and one in Gauteng) with a number of graduates with hearing impairment who had managed to find gainful employment after leaving university. Data were generated by means of semi-structured interviews with six graduates; three from each university. Use was made of ATLAS.ti to code and analyse the data using grounded theory methods, allowing for the discovery of recurring themes. The major findings which emerged from this study will be presented as well as the conclusions and recommendations.

Key words: *deaf, hearing impaired, graduate, employment, work, workplace, transition*

4. Social economic factors associated with labour force participation in selected African countries

Gowokani Chirwa, Alister Munthali, Arne Eide, Hasheem Mannan, Mutamad Amin, Leslie Swartz, Peter Mvula, Levison Chiwaula and Mac Maclachlan
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Labour is one of the most important resources for the poor in both developed and developing countries. Persons with disabilities, however, experience barriers in labour force participation. This paper, based on the Equitable Study conducted in 4 African countries namely Malawi, Namibia, South Africa and Sudan, aims at determining the socio-economic factors which are associated with labour force participation. In all the participating countries the study was conducted in both rural and urban areas. A screening questionnaire developed by the Washington Group on Disability statistics was used to identify persons with disabilities. A household questionnaire was administered to same number of case as well as control households. Labour force participation was classified in terms of, not working, paid employment and self-employment. The study used univariate, bivariate and multivariate data analysis. The sample comprised of 9307 respondents of which 1577(16.9%) were below the age of 16

and 7730 (83.1%) were above the age of 16. Furthermore 4616 (49.6%) were disabled individuals and 4691(50.6%) were not disabled individuals. The results showed that negative attitudes towards persons with disabilities were negatively associated with labour force participation. More to this, people with disability were less likely to be in employment. Additionally, there was existence of nonlinearities between age and labour force participation, implying that that the younger are less likely to have a job but there is a threshold beyond which senior have difficulty to fit in the labour market. Furthermore, looking across gender, we can confirm that there is a “gender disability burden for women. As evidenced by a negative sign on the coefficient meaning that women with disability are less likely to be in employment of all categories as compared to men.

Key words: *Persons with disabilities, employment, labour*

5. Access to Assistive Technology in Southern Africa

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The United Nations Convention of the Rights of Disabled People (CRPD) state that assistive technology (AT) should be made accessible and affordable to individuals with disability (for instance Articles 20 and 21). Assistive devices are important means for individuals with different types of impairments to participate fully in society. In most low-income countries, supply of assistive devices is however very far from meeting the demand. This contributes to reduce for instance mobility and accessibility of information, and thus to reduce individuals' opportunities for participation. It adds to this that much of what is available may not be suitable for the specific environmental challenges in low-income countries, and that services, assessment, adaptation, maintenance and follow-up is not available. Establishment of professional service delivery systems for assistive devices is necessary to ensure an effective provision of assistive devices to those who need it. Evidence on the need for devices and services as well as the state of current supply systems is crucial for any viable upgrading and up-scaling of AT services. This presentation draws on 7 national surveys that have been conducted over the last 12 years in southern Africa and aims at presenting a comprehensive picture of access to AT and AT services for individuals with disability in the region.

Key words: *assistive technology, mobility, disability, Africa*

6. An Exploration of Employment Experiences of Students with Disabilities who have Studied at UKZN

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Studies have indicated that people with disabilities in South Africa and across the world have difficulties in securing employment. The medical approach towards disability still contributes to the negative attitudes, ignorance and stereotypes employers have about people with disabilities. The main aim of the study was to explore employment experiences of students with disabilities who have studied at the University of KwaZulu-Natal. The objectives of the study included identifying barriers to employment and obstacles that exist once employment is obtained, identifying university programmes available to help students with disabilities gain employment access, and also recommending strategies that can be implemented to meet the employment challenges of students with disabilities studying at the University of KwaZulu-Natal. In addition, in order to

understand the barriers to employment, the impact of education on the employability of students with disabilities was explored. The study was qualitative in nature and in-depth interviews were conducted. Of the 21 participants interviewed in this study, 8 participants had physical disabilities, 9 were totally blind and 4 were partially sighted. Forty three percent of the participants acquired their disabilities at birth, 28% between 1 month to 12 years old and 39% due to environmental factors. Emerging themes from the transcribed interviews were analyzed. The study has found that graduate students with disabilities are still confronted with challenges in obtaining employment. Contributing factors included that employers were reluctant to employ them, apparently fearing that they would not be able to cope on the job and because there might be additional costs incurred if they were employed. Other factors related to difficulties in accessing job advertisements, inaccessible public transport and venues. In addition, the study has found that participants obtained qualifications they never wanted because special schools did not provide them with an adequate range of subjects, and that some academic departments at the University of KwaZulu-Natal were unwilling to admit them to programmes they preferred. This has contributed to unemployment as some qualifications received had no specializations. Also, participants felt that University of KwaZulu-Natal did not fully prepare them to the world of work.

Key words: *disability, employment, education, South Africa*

7. The Student Teacher with Visual Impairment: Perceptions from Stakeholders

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In Zimbabwe, persons with VI have been excluded in teacher education programs until recently. This study sought to find out stakeholders' perceptions of the pre-service student teacher with visual impairment. Qualitative interviews were conducted with student teachers at a teacher education institute, the lecturers, the institute administration, heads and staff of its attachment teaching practice (ATP) hosting schools, and the University of Zimbabwe's Department of Teacher Education (DTE) personnel. Findings of the study indicate an initial hesitation amongst stakeholders in dealing with the VI student teachers, which eases up with continued interactions. Stakeholders are positive about the inclusion of this category of student teacher in teacher education programs. However, concerns were raised on lack of ongoing awareness on inclusive education and inadequate support for the visually challenged student teacher in the lecture rooms and during ATP. Recommendations to improve the institution's inclusive education model are made.

Key words: *Visual impairment, special needs education, Zimbabwe*

8. Epidemiological Assessment of Childhood Disability in Two Districts in Malawi Using the Key Informant Method

Myroslava Tataryn, Dr. Linda Chokocho, Dr. Wakisa Mulwafu, Dr. Petros Kayange, Christiane Noe, Sarah Polack, Chris Lavy, Hannah Kuper

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Data on prevalence and causes of childhood disability are lacking in Malawi and generally in Low and Middle Income countries (LMICs) hampering effective service planning and evidence-based advocacy for children with disabilities. The objective of the study was to use the Key

Informant Method in Ntcheu and Thyolo districts to a) estimate the prevalence of moderate/severe physical, sensory and intellectual impairments and epilepsy in children and b) estimate rehabilitation and other service needs. Five hundred key informants (KIs) from the community were trained in identification of the impairment types included in this study. Identified children were invited to attend a screening camp where they underwent assessment by medical professionals. Approximately 15,000 children were identified by KIs as potentially having a disability of whom 7220 (48%) attended a screening camp. The estimated prevalence of impairments/epilepsy was 17.3/1000 children. Physical impairment (39%) was commonest impairment type followed by hearing impairment (27%), intellectual impairment (26%), epilepsy (22%) and vision impairment (4%). Approximately 2100 children per million population could benefit from physiotherapy and occupational therapy and 300 per million are in need of a wheelchair. An estimated 1800 children per million population have hearing impairment caused by conditions that could be treated or prevented through basic primary ear care. Only 50% of children with epilepsy were receiving medication. Corneal opacity was the leading cause of vision impairment. School attendance varied by impairment type and was lowest among children with multiple impairments (38%). This was the first study to use the KIM to estimate the prevalence of childhood disability in an African country. As well as providing data on child disability and rehabilitation and referral service needs that can be used to inform planning and advocacy of interventions for improving the quality of life of children with disabilities, this method study also has an important capacity building and disability awareness raising component.

Key words: Childhood *disability*, *key informant method*, *Malawi*, *physical impairments*, *sensory impairments*, *intellectual impairments*, *epilepsy*, *service needs*.

9. Getting the full picture

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Despite global MDG efforts, in real life little has changed in the life of persons with disability. It is well known that these efforts are to address issues of women and girls with disabilities, as they suffer most in poor African societies. They encounter “double -discrimination”, are even more marginalized, deprived and excluded from society than men and very few opportunities to develop their skills and talents. There are still many barriers to overcome in accessing services, facilities and opportunities. Participation, inclusion and occupation, is a human right. The research aims at contributing to the development of Occupation Just Communities, where everybody can participate and integrate in society and feel they belong. Objectives include enhance understanding of life experiences of women and girls with disabilities, enabling personal development of skills for occupation, participation and inclusion in society and enable social change and social action. This study will employ a qualitative design which combines participatory/emancipator and social action research. Target group is women and girls with disability in Southern Africa. A convenient study sample in Zambia, Zimbabwe and Malawi, through mixed-probability and purposeful sampling will be used. Multiple qualitative data collection methods will be used, including Narrative, Critical Incidents, participatory digital and visual methods. Being in the first phase, we are networking and seeking collaboration with persons with disability, as key experience experts, to include them as research assistants. We are sampling, piloting and networking. Women and girls with disability are keen to take part in the research. It is time for persons with disabilities to demand being included in Disability research. It is time to scale up Disability research as viewed from a human rights perspective, as participation and inclusion in society is a right for all. Together, we can go forward.

Key words: *empowerment, occupation, participation and integration*

10. Exploring how students completing the Post-Graduate Diploma in Disability Studies at the University of Cape Town understood made meaning of the experience of disability in Africa

Colleen Howell: University of Cape Town

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This paper is concerned with exploring how students completing the Post-Graduate Diploma in Disability Studies at the University of Cape Town understood and made meaning of the experience of disability in Africa. The students' understandings were captured through posters, which they produced as part of their academic requirements for a course on *Introduction to Disability as Diversity*. The students, as citizens of different African countries, were required to capture pictorially their understanding of the experience of and responses to disability in the African context and those factors that they felt were important to shaping and constructing understandings of disability across the continent. The paper moves from the assumption that what emerges from the students' posters provides valuable insights into the complex social, political and economic factors that influence and shape the construction of disability in Africa and thus what influences how disability is responded to by communities, governments and the broader society. The paper argues that these insights are especially important to existing conceptual thinking around disability. It suggests that grappling more carefully with the experience of disability in Africa not only brings into these debates much needed voices from 'the South', but also deepens these debates in valuable and necessary ways.

Key words: *special needs education, persons with disabilities, South Africa*

9.4 DEVELOPMENT PROCESS IN AFRICA: POVERTY, POLITICS, AND INDIGENOUS KNOWLEDGE SYSTEMS (D)

Overall facilitator: Judith van der Veen and Lieketseng Ned Matiwane

SESSION 1: KEYNOTE SESSION

Chair: Mapopa Mgombera

14:00 – 14:10 Welcome remarks and outline of the programme

14:10 – 14:30 Key note address: *Theresa Lorenzo*: Innovative practices of community disability workers that Facilitate inclusive development in rural areas of South Africa, Botswana and Malawi

14:30 - 14:40 Keynote responses

SESSION 2: DEVELOPMENT PROCESS IN AFRICA

Chair: Leiketseng Ned- Matiwane

14:40 – 14:55 *Nathaniel Kamban*: Promoting Universal Access to Water, Sanitation and Hygiene through Low-Cost Adaptations in Mali

14:55 – 15:10 *Steven Msowoya*: The Process of Mainstreaming Disability on the Public Sector: Lessons From Malawi's experience

15:10 – 15:25 *Razaka Ralphine*: Women with Disabilities in Madagascar Advocate for their Rights

15:25 – 15:40 *Lifah Sanudi and Stine Hellum Braathen*: Cultural Belief system, access to health services and Disability in Malawi

15:40 – 15:55 *Alexander Chikonga*: Increasing survival and reducing poverty of disabled children and Adults in Malawi to meet the MDGs

15:55 – 16:10 **Questions and responses to the 5 presentations**

16:10 – 16:20 **Picking-up a cup of tea**

SESSION 3: POVERTY AND POLITICS

Chair: Nathaniel Kamban:

16:20 – 16:35 *Mapopa Mgombera Shaba*: Malawi Union of the Blind: A Partner in Development

16:35 – 16:50 *A.P. Sefasi*: Assessing factors that affect access and use of health care services by people with Disabilities: a case study of Zomba district

16:50 - 17:05 *F. Nsengiyumva*: Christ's teaching on Miracles: A Challenge to the Agencies Working for People Disabilities

17:05- 17:20 *Mussa Chiwaula*: Living Conditions among people with disabilities in Southern Africa

17:20-17:35 *A.P. Sefasi*: Assessing factors that affect access and use of health care services by people with disabilities: a case study of Zomba district

17:35 – 17:50 **Questions and responses to the 5 presentations**

Session 4:

Chair:

17:50 – 18:10

18:10 - 18:30

COMMISSION DISCUSSION, RESOLUTIONS, RECOMMENDATIONS & AND WAY FORWARD

Judith van der Veen

Feedback & summary of key issues from the presentations - Rapporteurs

Prioritizing, action plans, resolutions, recommendations & and way forward commission chairs to report the following day

Theresa Lorenzo



Theresa Lorenzo is an Associate Professor in the Department of Health and Rehabilitation Sciences, Faculty of Health Sciences at the University of Cape Town. She gained experience in community-based disability and development programmes in the rural communities of Limpopo and Mpumalanga, South Africa, where she was part of a team that developed the community rehabilitation worker training programme with the Occupational Therapy department at University of Witwatersrand. Theresa obtained her MSc in Community Disability Studies from University of London in 1994. She joined UCT's Occupational Therapy department in 1996 and has worked with the SACLA Health Project, a primary health care NGO in building undergraduate students' capacity to work with civil society organizations in addressing the needs of disabled people and their families. She initiated the Disability Studies Postgraduate Programme at UCT in 2003 to bridge the gap between activism and scholarship. In 2012/2013 they piloted a higher certificate in Disability Practice for community workers.

ABSTRACTS IN ORDER OF PRESENTATION

1. Innovative practices of community disability workers that facilitate inclusive development in rural areas of South Africa, Botswana and Malawi

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Persons with disabilities and their families still experience stigma and a high degree of social exclusion especially in rural areas which are often poorly resourced and serviced. Disability-inclusive development requires a workforce equipped with skills to work intersectorally and in transdisciplinary manner in order to operationalise the community based rehabilitation (CBR) guidelines that will promote delivery of services in remote and rural areas. This paper explores the local experiences and practices of community-based disability workers (CDWs) in resource-limited rural communities in Botswana, Malawi and South Africa. It explores CDWs' activities and strategies to contribute to improving the lives and increasing the levels of social, economic and political inclusion of people with disabilities, their families and communities. A qualitative interpretive approach informed by a life history approach and phenomenology was adopted. Purposive sampling was used to select 16 CDWs who had at least five years' experience of disability-related work in a rural area. In-depth interviews were conducted by postgraduate students in Disability Studies. An inductive and interpretative phenomenological approach was used to analyse data. Three main themes emerged demonstrating the competences of CDWs: first, integrated management of health conditions and impairments within a family focus. Second theme was negotiating for disability-inclusive community development. Thirdly, coordinated and efficient intersectoral management systems. These competences draw from different disciplines which necessitates recognition of the CDWs as a cross-disciplinary profession. They contribute to building relationships which restore the humanity and dignity of the disabled person in their family and community.

Key words: *CBR, community disability workers, rural areas, development, poverty, policy implementation*

2. Promoting Universal Access to Water, Sanitation and Hygiene through Low-Cost Adaptations in Mali

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Research teams from Messiah College (USA) conducted a study to assess means of facilitating access and use of water and sanitation facilities for persons with disabilities (PWD) in Mali. World Vision's ***Water, Sanitation and Hygiene*** (WASH) project has sought to enhance hygiene and health among communities through the installation of hand-pumps and latrines. Until recently, little attention has been given to assure these facilities are inclusive of PWD. The study utilized a random-sample of 870 household survey and participatory appraisal methods to assess needs and prioritize objectives. As part of this process, 244 PWD were identified and interviewed. Results from these activities led to the identification of the following domains of intervention: access to and use of hand-pumps, transport and domestic use of water and access to and use of latrines. Low-cost modifications and assistive technologies designed to assist PWD in each of the three intervention areas were developed with the

assistance of local PWD. The modifications and technologies were tested and disseminated in target communities. Examples include: accessible pump superstructures, latrine chairs and tipping devices for water containers. In Mali, over 200 modified pump superstructures have been constructed. A parallel result was the advocacy role the study played (among target communities and development workers) for PWD. World Vision has expanded this work to the countries of Niger, Ghana, Malawi and Zambia. All of the countries are redesigning their WASH facilities and sensitization workshops have been conducted for all staff levels. In several of the countries, full-time local WASH and Disability coordinators have also been hired.

3. The Process of Mainstreaming Disability on the Public Sector: Lessons from the Malawi Experience

Steven Msowoya

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Informed by a baseline study of 2011 on the situation of disabled persons in Malawi, the Government of Malawi in collaboration with the umbrella for disabled people's organizations and international development partners is implementing steps to mainstream disability in the public sector. The objective of this paper is to describe Malawi's disability mainstreaming experience, positive outcomes and systemic challenges to date. Efforts to mainstream disability include several key activities. The Ministry for Disability has signed a Memorandum of Understanding (MOU) with development partners, committing itself to mainstreaming disability across sectors. Selected ministries and departments have been sensitized on disability rights and inclusive development. Disability focal persons have been appointed and trained alongside other key personnel in sectoral ministries as have members of district development committees. On-going mentoring and monitoring of mainstreaming efforts in sectors is being done. Disability awareness materials and a dissemination strategy have being developed. Disability legislation has been harmonized with current human rights and inclusive development practices. Lastly, documentation of results for disabled persons is being prioritized. An increased number of sectoral ministries and departments have incorporated disability in their strategic plans, funding, monitoring and reporting routines. A national advisory and coordinating committee on disability is providing policy direction, facilitating networking and overseeing implementation of mainstreaming efforts. In spite of these positive developments, systemic challenges have been observed including the following: staff appointed as disability focal persons lack authority to prioritize disability on the development agenda of their sectors and incomplete devolution of powers to local governments has led to dependence on central government for policy direction on including disability in development agendas of local governments. In this regard the way forward to realization of disability inclusive development is to create an enabling policy and legal framework, improved awareness and networking.

Key words: *Public sector, disability mainstreaming, inclusive development, disability rights, disability focal persons, systemic challenges.*

4. Women with Disabilities in Madagascar Advocate for their Rights

Razaka Ralphine

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Women in Madagascar are considered as second class citizens. Though they belong to the big group of women who are already undermined in general in the country, they remain the least and the last because of their disability. Though they belong to the group of persons with disabilities,

they have extra difficulty in life because of their women status. The general objective of the research is to provide detailed information on the reality on women with disabilities conditions of life. The specific objectives are to provide women with disabilities with capacity building which help them develop their knowledge on the Rights of persons with disabilities. Women with disabilities are encouraged to organize advocacy campaigns. Activities are expected to show the Network visibility and help people know more on women with disabilities and their difficulties and also how to collaborate with them. The methodology consists in gathering information related to women with disabilities. Advocacy campaigns are organized and undertaken by women with disabilities themselves on their Rights. Women with disabilities are supposed to be actively involved in all the stages of the research. The results are the involvement of women with disabilities in all the activities. The society is aware of their existence, what they are able to do specifically in advocacy for their rights. In conclusion the research is aimed at pointing on the lack of knowledge on the reality of women with disabilities' conditions of life from the society. Effort is provided from the Network to push the women with disability to advocate for their Rights and make themselves more visible.

Key words: *women with disabilities and their rights, undermined, second class citizen, least, last, lack of knowledge, visibility, capacity building, advocacy campaigns, and involvement.*

5. Cultural belief system, access to health services and disability in Malawi

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The relationship between cultural belief systems and disability emerged through a qualitative study on access to TB and HIV services for people with disabilities in Malawi. When examining origin of disabilities, some researchers have shown the role of illness as a cause of disability, but little has been said about the role of belief systems in affecting access to health care services to illnesses that contribute to impairing incidents. This paper discusses the linkage between belief in witchcraft towards illness, access to health care services and disability in Malawi. The study design was qualitative with an open and exploratory approach. Data were collected in Machinga District in Malawi through in-depth interviews, focus group discussions and participant observation. Most respondents in the study acquired their disability after birth due to illnesses. The commonly reported illnesses included polio, meningitis and malaria. Belief in the role of witchcraft as cause of their illness led people to prioritize accessing health care services from traditional healers where the care-seekers were often given inappropriate diagnosis and treatment. Most respondent reported that they did not visit modern health providers and where they did, it was only after the traditional healers had failed. Failure or delay in accessing health services from modern providers led to disabilities that could have been prevented for many of the study respondents. Strong belief in witchcraft as causes of illness and the resultant prioritization of seeking health care from traditional healers result in preventable disabilities. This study illustrates that some disabilities are still being acquired due to strong beliefs in witchcraft and traditional medicines. Increasing health literacy; knowledge and understanding about disease, which is generally very low would encourage people to access health services from modern health service providers. Until people are encouraged to prioritize accessing health care from modern health services, preventable disabilities caused by illness will prevail.

Key words: *HIV, TB, disability, Malawi*

6. Increasing survival and reducing poverty of disabled children and adults in Malawi

Alexander Chikonga: The Motivation Charitable Trust

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Motivation is an international development organization whose mission is to enhance the quality of life of people with mobility disabilities around the world. In December 2013 Motivation initiated a three-year project funded by the UK Department for International Development (DFID) in Malawi. Focusing on key Millennium Development Goals, the project targets some of the poorest, most marginalized groups in Malawi, and will address areas highlighted by this symposium including universal primary education and combatting HIV/AIDS. The project will increase survival of children with cerebral palsy and reduce the poverty they and their families live in and empower parents/carers to care for their children and linking them to income. It will also generate activities (IGAs) and HIV/AIDS programmes. It will also provide greater mobility for people with mobility disabilities, improving their survival, health, independence and potential for inclusion; it will ensure that children with mobility disabilities can access primary education and empower disabled people through peer-to-peer training on independent living, and link adults to HIV/AIDS programmes. Working with key partners in Malawi, including FEDOMA and MACOHA, Motivation will focus on building capacity to deliver on the above objectives in five districts, linking to existing activities, specifically on IGAs and HIV/AIDS programmes to ensure that they are accessed by disabled people. The project will provide mobility to 2,000 people; empower 600 parents/carers of children with cerebral palsy with the knowledge to care for their children; link 1,000 parents/carers to IGAs and HIV/AIDS programmes; make 25 schools physically accessible to disabled children; empower 100 disabled adults and children through peer-training. This project includes ambitious targets to address the survival and poverty of disabled children and adults through a range of approaches. It involves robust monitoring and evaluation to qualify impact and provide information for other stakeholders in Malawi, recognizing a current lack of data to inform work in this sector.

Key words: *mobility disability, cerebral palsy, empowerment, inclusion*

7. Malawi Union of the Blind: A Partner in Development

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Established in 1994 as the Student Union of the Blind (SUB) with a view to looking into the educational affairs of the Malawian learners with visual impairment, the Malawi Union of the Blind (MUB), as it later came to be known, broadened its pedestal to incorporate a wide range of the individuals with visual impairment regardless of creed, age, sex and social status, among others. This was principally due to the large group of learners with visual impairment joining the union, the massive outcry by the general public with visual impairment to have a mouthpiece, the need to get rid of the prejudice the sighted world clings to when interacting with those with visual impairment and the aspiration to partner with the government in its national development agenda, to list but some. Since the attainment of its new name in 2000, the union has been working round

the clock to have her objectives materialized. Advocacy, the tool through which the union penetrates itself into the minds of the country's citizenry, has been the order of the day. Through this, the game played between the sighted world and its visual impairment counterparts has been a reciprocal one in that both have advantaged the existence of the other. While the individuals with visual impairment depend on their sighted counterparts for associate membership and lobbying their organizations to consider those with visual impairment when strategizing their activities, among others, the sighted world depends on the ones with visual impairment for economic gains. Following their various levels of education, they are able to be employed. The money earned is used on the buying of and paying for various commodities and services. Organizations/individuals who are the recipients of the money in question pay taxes to the government, thereby, having the government itself expanding its economic base. In view of this, the Malawi Union of the Blind (MUB) to which most individuals with visual impairment belong, may be deemed a bonafide partner of the government in the development agenda. Fourteen years down the line, the union has registered some success in managing to overturn the tables of those who have been looking at disability as inability. Through some personal effort or positive discrimination, individuals with visual impairment have managed to attain appropriate educational levels. With these various educational levels, these individuals with visual impairment see themselves employed by different ministries (with the Ministry of Education, Science and Technology as the largest employer), government departments, NGOs and not forgetting faith groups. A direct contribution to the nation's development by these nationals with visual impairment is made through taxation. The presentation would be void of substance if the existence of the Malawi Union of the Blind (MUB) can go unmentioned. Nonprofit making though the institution is, it is able to employ various individuals, both those with visual impairment as well as their sighted counterparts. After getting paid, the union's employees join the rest of the general public in markets, shops, buses/minibuses and other places of a related sort where money changes ownership through the buying and selling of and paying for commodities and services. With the money received from the union's employees, the business institutions in question remit taxes to the government, thereby, broadening the nation's economic base. The government is thus, able to, through such an institution, realize some money for its development agenda. Economic empowerment is yet another activity through which the Malawi Union of the Blind demonstrates its partnership with the government in development. Farming, soap making and goat rearing are some of the activities the union embarks on to empower its members economically. Through such undertakings, those willing and industrious individuals with visual impairment are able to lead independent lives, thereby, ceasing being burdens on either their families or government. Furthermore, some individuals with visual impairment, bearing in mind that it may not be everybody penetrating into the white collar jobs, have ventured into their own firms to earn a living. With the proceeds realized, such individuals are able to purchase various commodities from shops. Needless, then, to say that this is a further contribution by those with visual impairment to the development of the country in that money various business institutions realize from the people in question is used by these same institutions to remit taxes to the government for its development agenda. In light of the above explanation, it would be observed that as an institution, the Malawi Union of the Blind (MUB), has managed to achieve the Millennium Development Goal 1. It is able to educationally and economically empower its citizens through the introduction of numerous activities. In so doing, poverty and hunger get eradicated among those with visual impairment as well as those who are sighted.

Key words: *Visual impairment, Malawi Union of the Blind, Malawi*

8. Assessing factors that affect access and use of health care services by people with disabilities: a case study of Zomba district

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The National Policy on Equalization of Opportunities for persons with disabilities in Malawi aims at ensuring that people with disabilities including children enjoy the same fundamental rights and responsibilities like any other member of the society. However, issues of access and usage of health care services remain a great challenge. The objective of the study is to establish factors that affect access and usage of health care services by people with disabilities. Both qualitative and quantitative methods were used to come-up with balanced findings. Using purposive and simple random sampling a total sample of 60 comprising of 40 people with disabilities and 20 healthcare personnel was drawn. The results show that 80% of people with disabilities reported that health care services are not accessible to them as they are located far from them and this is compounded by difficulties of transportation. 50% of people with disabilities reported various challenges with usage of health care services which include; prejudices by both health professionals and fellow patients, lack of appropriate medications and specialized personnel and departments. While 40 % of health care professionals stated that lack of specialized training makes them feel uncomfortable to attend to people with disabilities while 60% reported attending people with disabilities with promptness but that sometimes they lack appropriate medication while a few reported that people with disabilities as ‘problem’ patients in hospitals because they demand a lot. Thus, challenges faced by people with disabilities range from long distances to a health facility, poor transport, stigma held by health professionals and lack of specialized departments and professionals.

Key words: *Disability, healthcare, Discrimination, access.*

9. Christ’s teaching on Miracles: A Challenge to the Agencies Working for the People with Disabilities

Dr F. Nsengiyumva

The issue of disability is not something new in Malawi because it was there even before Christ was introduced to the African continent. In addition to that, you and I are reminded that a conference debating on people living with disabilities was held here in Malawi at the Bingu Conference Center in Lilongwe not later than last year bringing together delegates from many African nations. But, the fact that this International Conference is again held here in Malawi this year serves as a clear indication that the topic is of interest not only for Malawi but also for our contemporary world. And there is no doubt that this conference is going to debate the burning issues affecting people with disabilities. The question arising here, however, is what role the delegates of conferences accord to the individual concerned. To respond to the above question, this paper suggests that we seek inspiration from Jesus’ teaching to help us discern our model.

10. Living Conditions among people with disabilities in Southern Africa

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When working with disability rights in developing countries, one of the major obstacles is the lack of statistics and data of people with disabilities. It for this reason that a series of studies on living conditions of Persons with Disabilities were initiated by the Norwegian Federation of

Organizations of Disabled People (FFO) and Southern Africa Federation of the Disabled (SAFOD) in 1998. The studies respond to an international demand for quality data on disability in poor countries, as for instance explicitly stated in the UN Convention on Rights for People with Disabilities (CRPD). The first survey was in Namibia, then Zimbabwe, Malawi, Zambia, Mozambique, Swaziland, Lesotho and one is currently being implemented in Botswana. Through a participatory research approach, Disabled People's Organization's (DPOs) have been involved in the whole process from design development, implementation and utilization of results. A large number of individuals with disabilities have been involved at different stages of the research process. A comprehensive network has been established in the wake of the studies and SAFOD and the national affiliates have experienced increased interest from international donors leading to further participatory research on disability in the region. The objectives of this paper are not only to share with delegates the key findings and recommendations of the studies but also most importantly to illustrate the impact the evidence drawn from such studies have been utilized within the disability movement in Southern Africa at both policy and community levels. In conclusion, the paper will demonstrate practical strategies and best practices that have been used to deal with some of the issues cited above. It shall focus on successes and challenges that different stakeholders have gone through as regards mobilization of leadership and commitment at all levels with a view to promoting the rights of persons with Disabilities.

Key words: *SAFOD, living conditions, persons with disabilities, southern Africa*

9.5 HEALTH AND HIV&AIDS (E)

Overall facilitator: Margaret Wazakili and Jill Hanass-Hancock

SESSION 1: KEYNOTE SESSION

Chair: *Mutasa Jane:*

14:00 – 14:10 Welcome remarks and outline of the programme

14:10 – 14:30 Key note address: *JJ Llyod and JS Philips:* Factors contributing to the risk and vulnerability to HIV Infection among individuals with spinal cord injuries in South Africa

14:30 - 14:40 Keynote responses

SESSION 2: HIV&AIDS

Chair: *Jill Hanass-Hancock*

14:40 – 14:55 *Margaret Wazakili, Gubela Mji, Siphokazi Cghaza, Donald Skinner and Gert Vanrooyan:* Discrimination Hinders Access to HIV/AIDS and Reproductive Health Services for People With Disabilities in Malawi and Namibia

14:55 – 15:10 *Stine Hellum Braathen and Lifah Sanudi:* Household experiences of disability and HIV/AIDS in Malawi

15: 10 – 15:25 *Oyuu Iyute Deborah:* Improving access to Sexual Reproductive, HIV and AIDS services by Persons With Hearing Impairments: A case study of Uganda

15:25 – 15:40 *A.P. Sefasi:* Impact of HIV and AIDS on the Elderly: A case study of Chiradzulo District.

15:40 – 15:55 *Julie Schurgers:* Giving Children with HIV/AIDS: a future

15:55 – 16:10 **Questions and responses to the 5 presentations**

16:10 – 16:20 **Picking-up a cup of tea**

SESSION 3: HEALTH

Chair: *Oyuu Iyute Deborah*

16:20 – 16:35 *Frances Emily Owusu-Ansah, Harry Tagbor, Mabel Afi Togbe:* Access to health in city slums: The case of Sodom and Gomorra in Accra, Ghana

16:35 – 16:50 *Mutasa Jane:* An exploration to establish sexual reproductive health practices of adolescents with Hearing impairment in greater Harare, Zimbabwe

16:50 – 17:05 *Anthony K.Edusei and Elizabeth Adams:* Perceptions of Persons with Disability (PWD) on their Sexual and Reproductive Health at Dunkwa-On-Offin, Ghana

17:05 – 17:20 *Roy McConkey and Amy Shellard:* The Health of Youth with Intellectual and Development Disabilities in Lower Income Countries

17:20 – 17:35 **Questions and responses to the 4 presentations**

SESSION 4: COMMISSION DISCUSSION, RESOLUTIONS, RECOMMENDATIONS & AND WAY FORWARD

Chair: ***Margaret Wazakili***

17:35 – 18:05 Feedback & summary of key issues from the presentations - Rapporteur

18:05 - 18:30 Prioritizing, action plans, resolutions, recommendations & and way forward

Jacques Lloyd



Mr. Lloyd (Jacques as he is known) is a person living with a Spinal Cord Injury, but functioning at a very high pace! During the last 25 years he has been working and studying internationally and in South Africa in the field of health and rehabilitation for people with disabilities. He studied Sport Science at Stellenbosch University, specializing in physical rehabilitation for people with disabilities and after this completed his Master's degree in Belgium and Norway focusing on Adapted Physical Activities, Physical Education, Rehabilitation Sciences and Physiotherapy. He is currently enrolled as doctoral student at the University of the Western Cape focused on the field of disability, HIV/AIDS and TB infection.

Mr Lloyd has been involved in numerous disability rehabilitation, health, HIV/AIDS and TB related activities including:

1. Appointed by the Minister of Health as disability consultant to serve on the National Department of Health Disability and Rehabilitation Task Team 2013/2014
2. Invited by the Minister of Health to participate in a Civil Society Consultation on the National Health Insurance (NHI) and disability related health matters
3. "Global Fund Program" as practical coordinator and spokesman (2010 – 2013) with the aim to train persons with disabilities as community-based Peer Supporters
4. Assigned to represent the Disability Sector (SADA) on the Civil Society Forum of the South African National AIDS Council (SANAC) from 2012 till 2016.

He is a member of various DPO's and has represented organizations on provincial, national and international level.

ABSTRACTS IN ORDER OF PRESENTATION

1. Key note address: Factors contributing to the risk and vulnerability to HIV infection among individuals with spinal cord injuries in South Africa.

JJ Lloyd and JS Phillips

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HIV/AIDS has made a huge impact on human development and sexual reproductive habits in this century in the world and especially in sub-Saharan Africa. It has only recently been acknowledged that HIV/AIDS has an equal if not greater effect on or threat to people with disabilities. Survivors of traumatic spinal cord injury (SCI) with resultant disability are incorrectly believed to be sexually inactive, unlikely to use drugs or alcohol and at less risk of violence or rape than their non-disabled peers. This group can thus be described as economically, educationally and socially disadvantaged, which in itself, suggest that they are a high-risk group for HIV infection.

The overall objective of this study was to assess the factors that exacerbate the risk and vulnerability of individuals with spinal cord injuries to HIV infection in order to develop a more effective HIV intervention. A cross-sectional data from individuals with a traumatic spinal cord injury in 4 conveniently selected provinces in South Africa was collected by means of self-administered questionnaires which consisted of various sections requesting for information on: Demographics; HIV-Knowledge (HIV- KQ-18); Sexual behaviours; Sexual communication and negotiation skills and Self-efficacy to refuse sex. The results showed that the majority of the study sample was males (72.7%) with a mean age of 34.6 years. The majority also reported lifetime sexual intercourse (92.4%) but only 31.8% reported condom use with last sexual intercourse. Low level of HIV knowledge, and being male were the strongest predictor of risky sexual behaviours in this sample. In conclusion significant numbers of individuals with spinal cord injuries are thus engaging in risky sexual behaviours pointing to a need to strengthen comprehensive sexual health education to increase access to HIV testing, promote safe sex and condom use among this group.

Key words: *Human Immunodeficiency Virus (HIV); individuals with spinal cord injuries; risky sexual behaviours; HIV risk factors; sub-Saharan Africa*

2. Discrimination Hinders Access to HIV/AIDS and Reproductive Health Services for People with Disabilities in Malawi and Namibia

Margaret Wazakili, Gubela Mji, Siphokazi Cghaza, Donald Skinner and Gert Vanrooyan

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Southern African Federation of Disabled People commissioned a study to investigate the experiences of persons with disabilities in Malawi and Namibia. The objective was to identify challenges and design appropriate interventions. In this paper, we focus on the impact of discrimination on disabled people's access to sexual, reproductive health and HIV/AIDS services. This was a qualitative study in which individual interviews and focus group discussions were employed. The study was conducted in Blantyre and Windhoek cities respectively. A total of 30 male and female participants with disabilities were recruited. In each country we interviewed 10 key informants and conducted 4 focus group discussions of 5

participants in each group. All interviews were tape recorded and transcribed verbatim. A thematic content analysis was conducted. Data were organized according to similar codes and categories, from which main themes were generated to explain the data. In both countries, participants identified the age-old discrimination meted out to persons with disabilities as the main problem preventing them from accessing essential services. On the one hand, society continues to ignore the sexual, HIV/AIDS and reproductive health needs of this group. On the other hand, the group has been socialised to assume that a person with a disability is inferior, unattractive and asexual. Consequently, the group is excluded from mainstream programmes in spite of society's assumption that persons with disabilities have equal access to all programmes. The reality is that unless the group is specifically targeted, information and services made disability friendly, the group will continue to be marginalized, albeit unintentionally. SAFOD had envisaged that results from this study would inspire country-wide studies in the two countries and it can be replicated in other African countries under SAFOD's membership.

Key words: *HIV/AIDS, reproductive health, persons with disabilities, Malawi, Namibia*

3. Household experiences of disability and HIV/AIDS in Malawi

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There is a direct relationship between disability and HIV/AIDS. On the one hand, the side effects of the HIV/AIDS virus and ART-medication can result in disability, and on the other, people with disabilities are at equal or increased risk of being infected with HIV compared to non-disabled people (Rohleder et al, 2009; Hanass-Hancock, 2009; Groce et al., 2013). Despite this, research has shown that people with disabilities have largely been excluded from sexual health education and care (Groce et al, 2012; Hanass-Hancock, 2009; Rohleder et al 2009; Rohleder & Swartz, 2012). In an African context care givers play a crucial role in care seeking and giving for both adults and children. Primary care givers are usually members of the same household as the immediate care seeker, and hence illness and care seeking becomes a household issue, more than just an individual issue (Colvin et al, 2013). This presentation is based on a qualitative study exploring access to TB and HIV/AIDS services for people with disabilities in rural Malawi (2014). In-depth interviews with people with disabilities living with HIV/AIDS, their primary care givers in the household and health care providers from which they had sought care for HIV were carried out. This approach provided a broad understanding of the experiences and challenges not just of the disabled individual him/herself, but also of their household. Caring for a disabled or ill family member can place an added burden on already impoverished households. This presentation will explore household experiences of HIV/AIDS care giving and seeking among adults with disabilities and their care givers in Malawi. It will discuss how it affects households having a disabled and HIV positive member. It will also suggest possible ways to assist these households to care for this individual without compromising the well-being of the other members of the household.

Keywords: *disability, HIV/AIDS, care*

4. Improving access to Sexual reproductive and HIV and AIDS services by persons with Hearing Impairments: A Case study of Uganda

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Recent estimates provided by WHO indicate that one billion people (corresponds to around 15% of the world's population based on 2010 global population estimates), experience some form of disability. Of the one billion people, approximately 110 to 190 million encounter severe difficulties in their daily lives. In fact, most people with disabilities face obstacles at every turn in their lives. Article 25 requires states to ensure equal access to health services for PWDs, with specific mention of SHR and population-based public health programmes. Using case studies and pictures, the objectives of this paper is to increase the consciousness of HIV/AIDS service providers, development partners and policy makers on the issues and deaf persons in relation to sexual reproductive and HIV/AIDS programming and service provision. As noted in the 2009 WHO/UNFPA Report on SRH and Disabilities, PWDs as a group, fit the common pattern of structural risk for HIV/AIDS and other sexually transmitted infections (STIs), e.g. high level of poverty, high level of illiteracy, lack of access to health care and lack of power when negotiating safer sex. PWDs have the same SRH needs as other people as well as same rights. Yet they often face barriers to health information and services. Knowledge of and access to SRH services in particular for Deaf women and girls is insufficient. Illiteracy, lack of sign language interpreters and lack of deaf persons skilled in sign language seems to be the reinforcing factors.

Key words: HIV/AIDS, SRH, disability, hearing impairment, Uganda

5. Impact of HIV and AIDS on the Elderly: A case study of Chiradzulo District

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Older people in Sub-Saharan Africa are experiencing a lot of problems and most of them are due to HIV/AIDS. They are increasingly playing principal roles in caring for younger adults suffering from HIV/AIDS and orphaned grandchildren. The disease has affected older people in a number of ways like getting infected themselves, having their children suffer from the illness and their consequent death taking care of HIV/AIDS orphans. The objective of this paper is to unravel socio-economic impacts of HIV/AIDS on the lives of older people in Malawi following illness and subsequent death of their productive children. It also examines the magnitude of the struggles that older people undergo in caring for HIV/AIDS orphans. We used interviewer-administered questionnaire and focus group discussion to collect data from a sample of 116. The results reveal that older people have no alternative but to provide care and support to their ill children, and following the death of their children to become parents again in taking care of the orphaned grandchildren. This is particularly a big challenge in a country like Malawi, dependent on hand-hoeing for subsistence agriculture, where food production is very much dependent on your physical strength. 79% of older people taking care of HIV/AIDS patients or orphans were found to have limited or no information about HIV/AIDS. 31% were dependent on relatives for support, while 69% sustained themselves through piece-work, small businesses or farming. Older people need more resources and assistance to enable them fulfil their vital role in caring for HIV-AIDS sick children and their orphaned grandchildren. Preventive information regarding HIV/AIDS should reach older people.

Key words: Older people, HIV/AIDS, support, impact, gerontology

5. Giving Children with HIV/AIDS a Future

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With improvement of clinical management, ARV upscale, mortality in children has dropped and has transformed HIV/AIDS from a fatal disorder to a chronic illness. With that a relatively new phenomenon has emerged—children living with stigma, exclusion and reduced functional ability as a result of HIV/AIDS. How to go about in Occupational Therapy, to encourage, enable and equip these children to active optimal functioning within society? The objectives include understanding occurrence of developmental/ functional problems due to HIV/AIDS, identifying key issues for intervention, contributing to development of knowledge and evidence based practice for enhancing patient care and further research. Within the qualitative research design, literature review, ethnography, observation and case study method were applied. The target group included children between 2-10 years, diagnosed with HIV/AIDS and presenting with developmental delay/disabilities. The World Bank addressed in 2004 the need for interventions as scientific evidence showed that HIV/AIDS can affect children's development. Early OT rehabilitation & developmental intervention programs of HIV infected children are vital and helps to reduce the long-term consequences, equips children with productive life skills. This leads to more community understanding & awareness for the needs of these children and facilitates integration into society. The literature findings were supporting the clinical research findings in Zambia. This research highlights the importance of enabling the future of HIV-infected children. Additional research is necessary to understand the complex relationship between HIV/AIDS and disability, to assess the adequacy of the current response in the field of HIV-related rehabilitation and child development. Scale up of OT intervention programs, facilitating access to OT services in the community, further impact research on OT-based community intervention modalities in Zambia and Africa is recommended.

Key words: *occupational therapy, developmental delay, HIV/AIDS, children*

6. Access to health in city slums: the case of Sodom and Gomorra in Accra, Ghana

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Rapid rural-urban migration of people to cities is a reality around the globe that has increased city slum dwellers. Sodom and Gomorra is a city slum located in the heart of Accra, Ghana. Like other slums it lacks basic amenities necessary for dwellers' quality of life. This study describes residents' access to health and factors that affect use of health care facilities. Through purposive sampling, questionnaires were administered to obtain data on demographic characteristics, existent health facilities, users, health insured residents, and knowledge of common diseases. Many residents (71.2%) had never visited a health facility and relied on drug shops for their health needs. Education, health insurance, and good knowledge of common illnesses significantly reduced the likelihood of not using a formal health care facility. Compared to those without any education, respondents with primary [AOR = 0.48; 95% CI (0.26-0.86), p=0.01] or secondary education [AOR = 0.35; 95% CI (0.18-0.70), p=0.003] were less likely not to use health facilities. Good [AOR = 0.35; 95% CI (0.18-0.70), p=0.003] or fair [AOR = 0.35; 95% CI (0.18-0.70),

p=0.003] knowledge of causes, symptoms and prevention of common illnesses significantly reduced residents' likelihood of not using of health care facilities. Insured residents were also less likely not to have used a formal health care facility compared to the uninsured [AOR = 2.55; 95% CI (1.47-4.42), p=0.001]. For many neither distance (73.2%) nor transportation to health facility was a problem (74.1%) but access to transportation influenced the use of health facilities [AOR = 0.51; 95% CI (0.31-0.84), p=0.01]. Environmental hazards, overcrowding, poor-quality housing, and lack of health care in Sodom and Gomorra pose grave threats to the health of the inhabitants. Multi-sectoral interventions championed by the Ministry of Local Government are needed to alter the trend.

Key words: *Slum dwellers, health, access, Sodom and Gomorra, Ghana*

7. An exploration to establish sexual reproductive health practices of adolescents with hearing impairment in greater Harare, Zimbabwe

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The attainment of the valuable resource of increased life expectancy is a critical need for all persons. It is determined by many factors like possession of health related knowledge and observing rules for healthy living. These aspects become very important to populations that cannot access information in the same way as the hearing majority with sensory impairments such as those with deafness. By its very nature, deafness impedes spoken word communication and this in turn affects the health literacy and information accessibility process. This population's information reception channels are restricted by impairment and hence are at great risk of lack of information for protection against infection. It is vital that appropriate information seeking practices are established so that they may receive correct preventive and treatment information for healthy living. In this respect competence in the use of sign language becomes critical to all information dissemination personnel. This study set to ascertain the channels that this population used in gathering reproductive health information related to diseases such as HIV and AIDS and sexual transmitted infections. The mixed study methodology design which employed both the interview guides and questionnaires for data collection was used. Participants were deaf adolescents who resided in the greater Harare area. Results indicated that these adolescents experienced great communicative challenges in this endeavor despite the numerous mainstream health centres in Harare for health information dissemination. They did not access mass media information due to lack of literacy skills and also failed to access audio messages passed through the radio and television. Lack of signing skills by even teachers of the deaf, negative attitudes of the public, discrimination, shortage of resources and apathy by the deaf were among the many negative factors that characterized the practices of accessing health information by this population.

Key Words: *Health information, deaf, impairment, HIV and AIDS, adolescents, sexually transmitted infections.*

8. Perceptions of Persons with Disability (PwD) on their Sexual and Reproductive Health at Dunkwa-on-Offin, Ghana

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Worldwide, there is very little documented information related to sexual and reproductive health of Persons with disability. The study sought to assess the perceptions and practices of persons with physical disability and visual impairment on sexual and reproductive health at Dunkwa-on-Offin, in Ghana. With a total of 37 participants, a qualitative cross-sectional study using in-depth interview and focus group discussions were employed. The in-depth interviews targeted five personalities comprising one social worker who had worked with Persons with Disability (PWD) for over twenty years and four leaders, two each of the visually impaired and physically disabled associations at Dunkwa-on-Offin municipality. In addition, four focus group discussions with each involving 8 participants were held for physically disabled males and females, and visually impaired males and females. The study revealed that PWD are as sexually active as their counterparts without disability, desire to marry and have families, and desire to have children, though the larger society's stigmatization of Disability poses a strong barrier to the selection of suitable partners. They, however, do not perceive that their children would have any form of disability. On family planning, most of the PWD had heard of family planning and knew of its importance. However, most did not know of the various methods of family planning, whilst some also held misconceptions which discouraged them from using them. The study, therefore, recommends that PWD should be given adequate sex and reproductive health education, whilst the society continues to be targeted with education to change misconceptions about PWD, especially on matters related to intimate relationships.

Key words: *Physically Disabled, visually impaired, sexuality, reproductive health*

9. The Health of Youth with Intellectual and Developmental Disabilities in Lower Income Countries

Roy McConkey & Amy Shellard

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People with disabilities experience poorer health than their non-disabled peers. This is especially true of those with intellectual and developmental disabilities (IDD) although relatively few studies have been undertaken in low income countries. Special Olympics is an international movement that provides sports training and competitions in over 170 countries around the world to athletes with IDD. Their Healthy Athletes program offers health exams at local, national, regional and international Games. From 2007 onwards, these records have been collated into an electronic database with information on the overall health of over 66,000 athletes from around the globe. This paper contrasts the health of youth with ID (aged 8 to 19 years) in lower income countries of Africa, Middle East-North Africa, Asia-Pacific and Latin America with those living in higher income countries of North America and Europe. Secondary analyses of the Healthy Athletes dataset were undertaken using Binary Logistic Multiple Regression to identify significant predictors on selected health indicators of underweight, hearing and visual difficulties. The rates of underweight were particularly high in Asia and among males. Difficulties in hearing and vision are also reported. The lack of access to health services is likely to be a major cause for the poorer health of athletes with IDD. Special Olympics is piloting a Healthy Communities initiative in Malawi and South Africa (as well as in 12 other locations internationally) to educate families and health professionals in detecting and addressing the health needs of youth with IDD. Plans for evaluating the impact of these initiatives will be described.

Key Words: *Health, low income countries, intellectual and developmental disabilities*

9.6 SYSTEMS OF COMMUNITY BASED REHABILITATION (F)

Overall facilitator: Nondwe Mlenzana

SESSION 1: KEYNOTE SESSION

Chair: **Alick Nyirenda**

14:00 – 14:10 Welcome remarks and outline of the programme

14:10 – 14:30 Key note address: *Mary Wickenden and Lyness Manduwa*: Evaluating the impact of CBR: Progress report on a study developing an innovative participatory approach to impact Evaluation in Uganda and Malawi

14:30 - 14:40 Keynote responses

SESSION 2: COMMUNITY BASED REHABILITATION

Chair:

14:40 – 14:55 *Frances Emily Owusu-Ansah*: Depression, anxiety, flexibility and gastric symptoms

14:55 – 15:10 *A. Rhoda, A. Arowoia and N.Mlenzana*: Community re-integration of stroke patients in Western Cape, South Africa

15:10 – 15:25 *Judith McKenzie*: A systematic review of interventions to support families with an Intellectually disabled family member

15:25 – 15:40 *S.B. Statham, M. Kloppers, R.K. Felix, E. Pegram, C. Joseph, A. Rhoda, B. Protorius & G.Mji*: Measuring the Functional Rehabilitation Outcomes of Clients Entering the Rehabilitation Services at Four Sites in the Western Cape

15:40 – 15:55 *Marguerite Schneider, Leslie Swartz and Crick Lund*: Mental Health Disorders and Disability

15:55 – 16:10 **Questions and responses to the 5 presentations**

16:10 – 16:20 **Picking-up a cup of tea**

SESSION 3: COMMUNITY BASED REHABILITATION

Chair: **Judith Mckenzie**

16:20 – 16:35 *Nondwe Mlenzana*: Perceptions and Satisfaction of Caregivers Regarding Rehabilitation Services from selected Rehabilitation Centers in the Western Cape

16:35 – 16:50 *Josephine Adusei-Nkrumah and Frances Emily Owusu-Ansah*: Social Support and Depression in Persons with Disability in Ghana

16:50 – 17:05 *Alick Nyirenda and Svein Brodtkorb*: The CBR Zambia Support program: From piloting to evidence based program scale-up

17:05 – 17:20 *Lynn Cockburn, Shaun Cleaver, Ezekiel Benuh and Julius Wango*: Considerations about Researching Disability prevalence in Africa: an example from Cameroon

17:20 – 17:35 **Questions and responses to the 4 presentations**

SESSION 4: COMMISSION DISCUSSION, RESOLUTIONS, RECOMMENDATIONS & AND WAY FORWARD

Chair: ***Nondwe Mlenzana***

17:35 – 18:05 Feedback & summary of key issues from the presentations - Rapporteurs

18:05 - 18:30 Prioritizing, action plans, resolutions, recommendations & and way forward commission chairs to report the following day

Mary Wickenden



Dr Mary Wickenden is a senior research fellow in disability and development at the Institute for Global Health, part of University College London, UK. She teaches about disability on the MSc Global Health and Development and does mixed methods and qualitative research about disability in low income settings. Mary originally trained as a speech and language therapist and worked clinically mostly with young children with severe disabilities and their families both in the UK and in India. She then became interested in disability more broadly, in low income settings. She trained as a medical anthropologist, carrying out an ethnographic study of the lives of disabled teenagers. She has worked extensively in disability service development and research in South Asia and more recently in East Africa. She is particularly interested in understanding the lives of disabled children and their families and developing participatory research methods which enable people with all types of impairments to contribute to research in community settings. She is currently leading on an Australian Government aid funded research project developing a flexible participatory model and tools for evaluating the impact of CBR, being trialled in Malawi and Uganda.

Lyness Manduwa



Lyness Manduwa is a Malawian woman with a physical disability. She is married with three children. She has been involved in a number of disability research and advocacy projects. Lyness is the vice chairperson of the Association of the Physically Disabled in Malawi as well as their Public Relations Officer and a member of Disabled Women in Development. She is also the vice chairperson of Blantyre Community Based Rehabilitation Coordinating Committee and a Resource Person for Federation of Disability Organizations in Malawi. She has diplomas in Secretarial skills and Human Resource Management. In 2004 she completed a diploma in Research Methodology from University of Malawi (CSR) which was run in collaboration with SINTEF and FEDOMA. She has recently worked as a research assistant on the UCL (Australian government funded) project on developing participatory impact evaluation of CBR.

ABSTRACTS IN ORDER OF PRESENTATION

1. Evaluating the impact of CBR: progress report on a study developing an innovative participatory approach to impact evaluation in Uganda and Malawi

Mary Wickenden, Huib Cornielje, Marguerite Schneider, Erik Post, Rachel Gondwe, Steven Msowoya and colleagues from Malawi and Uganda
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Community based rehabilitation is promoted by WHO as the intervention model of choice to achieve increased wellbeing, participation and access to rights and equality of disabled people, particularly in under-resourced settings. This strategy for multi-sectoral inclusive development has been reconceptualised during the last decade, as described in the WHO CBR guidelines (2010). CBR is widely used throughout Africa, although in different forms. However evaluation of the impact of CBR is problematic. There is a lack of consistency of approach which makes assessment of the value of CBR and comparison across programmes challenging. The paper will present the findings so far from an on-going study in Uganda and Malawi. The research aims to develop an innovative and flexible model for outcome and impact evaluation of CBR, which will be usable in a variety of contexts and types of CBR programme. The research team have developed a model and toolkit for impact evaluation, based principally on Outcome Mapping. This mixed methods approach recognizes the nonlinear and complex nature of community interventions and provides ways of making processes participatory. This has not previously been used in the disability arena and we are combining it with other approaches, such as Most Significant Change, PADEV, Sensemaker and the 5Cs method. Initial pilots in Malawi and Uganda will yield preliminary data on which to base a more refined and finalized version of the tool. This paper will present the analysis from the initial fieldwork. It will discuss the successes and challenges experienced so far and the proposed adaptations to be trialled in the second stage of the study. The potential of Outcome Mapping alongside other methods to provide a new participatory approach to impact evaluation of CBR as a strategy for inclusive development will be described and critiqued.

Key words: *CBR, impact evaluation, Outcome Mapping, participation, community, Malawi, Uganda*

2. Depression, anxiety, flexibility and gastric symptoms

Frances Emily Owusu-Ansah, PhD
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Evidence on brain-gut connection abound as is the relation of depression and anxiety to gastric pathology. However, still elusive is clarity on specific cognitive and behavioural states and bowel functioning. This study investigated the relationships among depression, anxiety, flexibility, and gastric symptoms to elucidate the relation of emotional states and flexibility to gastric pathology. A total of one hundred and twenty students participated in the study and completed the four scales used: The Beck Depression Inventory (BDI), the General Expectancy for Success Scale (GESS), a Bowel Health Questionnaire (BHQ), and the Luchin water-jar problems. Correlational analysis showed a high correlation between BDI and the BHQ, especially for young male students. Scores on the Luchin water-jar problems were negatively correlated with the BHQ and the best predictor variable for scores on the BHQ was the BDI, followed by scores on flexibility (Luchin). A multivariate analysis revealed a

significant effect of Sex on the GESS, while univariate analysis showed a significant effect of Age on the same scale. The results suggest that depression, flexibility and gastric symptoms may be associated in nonclinical samples.

Key words: *Anxiety, depression, flexibility, gastric symptoms*

3. Community re-integration of stroke patients in Western Cape, South Africa

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Community re-integration is often a challenge for individuals who have suffered a stroke due to factors relating to the individual or the environment. The aim of this study was to determine and explore the various participation restrictions and identify possible ways of promoting community re-integration of stroke patient living in the community. A mixed methods approach was used to collect data. For the qualitative phase, a cross sectional survey was conducted, while the qualitative part consisted of focus group discussions. A convenient sample of stroke patients receiving treatment or had received treatment at selected Community Health Centres was approached to participate in this study. A purposive sample of those who were part of the quantitative part of the study was selected for the focus group discussions. The World Health Disability Assessment Schedule 2.0 (WHODAS 2.0) was used to collect the quantitative data. The Statistical Package for Social Sciences (SPSS) was used for descriptive and inferential statistics. Qualitative data was analysed thematically. One hundred and twenty participants were interviewed as part of the survey. The domains the participants had difficulty with was; staying alone for a few days (44%), ability to complete tasks properly (51.7%), engaging in social activities (50.8%), negative attitudes of others (39.2%). These aspects were further highlighted in the themes that arose from the focus group discussion. There is need to channel resources towards dealing with the various difficulties encountered by these stroke patients in the community, and ensure best available options to promote, and ensure stroke patients are well integrated into the society.

Key words: *Stroke, community re-integration social isolation, caregivers, community, South Africa*

4. A systematic review of interventions to support families with an intellectually disabled family member

Judith McKenzie

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Intellectual disability is defined by limitations in intelligence and adaptive behavior starting in the developmental period. These limitations require that individuals with intellectual disability receive lifelong support to achieve a satisfactory quality of life. Most people with ID across the world live with and are supported by family caregivers and in the family home. However, little is known about what support families receive or need in order to carry out their supportive role. This paper reports on a systematic review of the literature on interventions designed to support families in caring for a family member with ID. An initial database of over 2400 papers was gathered using a search strategy designed to pick up suitable articles. The database was then narrowed down into two categories: family support interventions in high income countries (HIC) and family support interventions in low income countries (LMIC). The selected articles were then examined with respect to a range of criteria and the

findings for LMIC were compared to those for HIC. The study found few papers on interventions that impact on families, with fewer in the LMIC group than in the HIC group. Amongst these papers there was greater concern with families of young children than of adults with ID. Different types of intervention and the staff required to carry out the intervention are also described. Despite the significant role that families play in supporting their family members with ID, there is minimal research into this area. There is a need to expand research into existing family support strategies and further innovative support interventions.

Key words: Intellectual disability, supportive roles of families, low income countries

5. Measuring the Functional Rehabilitation Outcomes of Clients Entering the Rehabilitation Services at Four Sites in the Western Cape

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The rehabilitation of physically disabled persons in the Western Cape, South Africa, takes place at various levels of health care and at a variety of institutions. There is general lack of evidence regarding the outcome and impact of these services. This research study critically analysed the patient functional outcomes at four sites offering rehabilitation services, within the Department of Health. Each site represents a different type of intervention and serves a different population. The theoretical frameworks of the International Classification of Functioning, Disability and Health and the Community Based Rehabilitation matrix were used. The methodology used was a longitudinal before and after study, where patients diagnosed with one of the five most prevalent conditions (at a site) were admitted into the study prior to the onset of rehabilitation, this gave the pre-test base line. The patients were retested three months later, after receiving rehabilitation, this formed the post-test measurement. A series of standardised tests, self-developed questionnaires, data collection tools were used to collect the information. The results were analysed using descriptive statistics and ethical clearance was obtained from the participating academic institutions. In total 335 patients were admitted to the study. The most prevalent conditions differed at each site as did the results to rehabilitation services. Results from the standardised tests EQ5D, Barthel Index, DASH, Ostwestry back pain scale, Arthritis Impact Measurement scale and Clinical mobility scale will be presented. The results of the Zambian scale for Participation will also be included. The most important similarities and differences from each site will be presented and discussed. Implications for Service delivery in the Western Cape include issues of accessibility, loss to follow up, results of consistency of treatment, and the importance of patient participation in decisions regarding their rehabilitation process.

Key words: rehabilitation outcomes, standardised rehabilitation outcome measures.

6. Mental Health Disorders and Disability

Marguerite Schneider, Leslie Swartz & Crick Lund

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This review paper explores the ongoing conceptual separation of mental disorders from physical and sensory impairments, or psychosocial disability from the more ‘traditional’ categories of physical and sensory disability. Mental health is an important component of health and wellbeing. Mental health disorders can and do lead to disability, as do physical and sensory impairments. The shift to talking about psychosocial disability signals growing inclusion of mental illness into the realm of disability. However, the oft used phrase ‘disabled people and people with mental illness’ suggests that we have not yet reached full inclusion and that consequences of mental health disorders are still understood as separate from disability. This paper reviews how disability is defined and explores the way in which mental health disorders fit within this definition usually applied to physical and sensory impairments. The different types of mental health disorders are discussed in relation to people’s functional status and identity as disabled, with a focus on confusions between mental illness and cognitive or intellectual disorders. The measurement of psychosocial disability and mental disorders are discussed in contrast to physical and sensory impairments in terms of accuracy of measures, and the impact on overall disability statistics.

Key words: *mental health, psychosocial disability, defining disability, measurement of disability.*

7. Perceptions and Satisfaction of Caregivers Regarding Rehabilitation Services from Selected Rehabilitation Centres in the Western Cape

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Rehabilitation aspects within health services often face challenges as they have to compete with resources for communicable diseases. With the movement of resources for rehabilitation in South Africa towards primary health care, it is essential that the views of the key role players are understood if effective rehabilitation of the patient is to occur. One of the key role players in the rehabilitation process is the caregiver. An increase in the number of disabled emphasizes the need for a better understanding of the rehabilitation services provided at primary care level. The objectives of this study were to explore the perceptions and satisfaction of caregivers regarding rehabilitation services in the Western Cape, South Africa and to inform clinical practice and policy in this emerging field. This was a qualitative study using semi-structured qualitative interviews. Rehabilitation service centers in South Africa, covering rural and urban locations were used in this study. A total of 26 participants were identified but 13 interviews were conducted with caregivers of patients with amputations (3), cerebrovascular accidents (5) and neuromuscular disorders (5). The themes highlighted included: (1) financial challenges with regards to transport; (2) caregiver-therapist relationships with regards to information sharing, and inclusion in rehabilitation process; (3) caregivers physical and emotional health and (4) Facility management. In conclusion, based on the current study the rehabilitation service seem to be meeting the basic rehabilitation needs of the patients however the needs of other role players like the caregivers needs attention.

Key words: *rehabilitation, disability, South Africa*

8. Social Support and Depression in Persons with Disability in Ghana

Josephine Adusei-Nkrumah and Frances Emily Owusu-Ansah

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Social support is one of the determinants of individuals' general wellbeing. Lack of or inadequate social support has been associated with depression in the general population. However, evidence from persons with disability has been more limited. The present study investigated the relationship between perceived social support and level of depression in Persons with Disability (PWD). 317 PWDs from some special basic schools in Ghana participated in the study. The Beck Depression Inventory Scale (BDI) and Multidimensional Scale of Perceived Social Support (MSPSS) were used to collect data which were analyzed using SPSS V. 16 software. Analyses included simple linear regression, chi-square and other descriptive analysis. Ethical clearance for the study was sought and obtained from the Committee on Human Research, Publications and Ethics, KNUST. Findings showed that greater perceived social support was associated with less depression in PWDs; however variance explained, though significant, was not high suggesting that other variables may underlie the etiology of depression in PWDs. Males were generally more severely depressed relative to their female counterparts. Respondents who acquired disability later in life had a significant depression level than those who were born with it (59.2% versus 40.8%; $p = 0.013$). Implications of findings are discussed emphasizing the importance social support and management of depression in PWDs.

Key words: *Social support, Depression, Disability, Ghana.*

9. The CBR Zambia Support Program: From piloting to Evidence based Program Scale-up

Alick Nyirenda and Svein Brodtkorb

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Background: The Norwegian Association for Persons with Developmental Disabilities (NFU) and the Norwegian Association of Disabled (NAD) have been undertaking regular surveys, studies and reviews (both internal and external) to better equip CBR volunteers, workers and policy makers with the evidence they need to undertake holistic, persons with disabilities-centred programs in selected CBR pilots districts of Kazungula, Zimba and Livingstone. A fully-fledged, government led CBR is now being implemented. The program is designed to facilitate a forum for capacity building, strengthening and competence utilization (of government structures and DPO's) through use of local, national, regional and international persons and research institutions in the CBR fraternity. A comparative study was done to assess the suitability of potential pilot zones (2011) and thereafter, an in-depth baseline survey was done in 2012. To date, a study on intellectual disabilities and a mid-term program review has also been conducted (2012). At the end of 2013, a post 2 year roll-out external evaluation of program the start-up phase was done to document progress and outcomes, comparing similar studies and their findings in Lesotho, Malawi and Zambia, where NAD is supporting mainstream CBR alongside a comprehensive documentation and research project. Informed by rigorous research done between year 2008 and 2014, the CBR Zambia program has improved its quality of work, undertaking informed, gradual scale-up using both the bottom-up and

top-down (community and policy) approach. More DPO's have been supported to reach more persons with disabilities, facilitate multi-sectoral networking and advocacy. Mainstream government structures have adopted CBR as its main strategy for reaching and supporting persons with disabilities in Zambia.

Key words: *CBR, research, evidence, results, practice, government-led, DPOs*

10. Considerations about researching Disability Prevalence in Africa: An example from Cameroon

Lynn Cockburn, Alexa Bramall, Emmanuel Anjonga, Shirin Kiani, Timothy Fanfon, Che Manasseh, Amasinda Grace, Mukong Nicholas, Evelyn Lukong, Kenchi Joseph, Ezekiel Benuh
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This article describes the BPG development process for practice guidelines in Cameroon. Evidence-based best practice guidelines (BPGs) are important for clinicians to provide optimal patient care and improve health care delivery. Although numerous BPGs for high income countries have been developed, few guidelines focus on improving health care in low income countries. There is a dearth of information illustrating the specific challenges of developing BPGs in resource-poor settings such as Cameroon. A ten step development process was devised based on input from local and international professionals. A working group was formed for each BPG topic. Meetings between members of the working groups and group leaders were scheduled to discuss BPGs, progress, challenges, and ideas for implementation. The BPG development process was implemented. Six priority topics for BPG development were identified, a team leader was assigned for each core working group of between 4-11 members. Since the formation of the working groups in 2009, a best practice community has developed with over 50 members, including local practitioners, students, and community advocates. The development of BPGs in Cameroon has been the focus of conferences, presentations and seminars, and five guidelines have been finalized. Some of the challenges included 1) a lack of knowledge or familiarity with BPGs; 2) difficulties maintaining the involvement of group members; and 3) Cameroon specific technological barriers. In conclusion the process of developing and finalizing BPGs in low income contexts can be facilitated through 1) the specification of an organized development process and timeline for completion; 2) the involvement of a diverse team of individuals, including local practitioners; 3) the inclusion of ongoing process evaluations; and 4) ensuring continuing commitment and communication amongst the team.

Key words: *Cameroon; Practice Guidelines as Topic; Rehabilitation; Developing Countries.*

9.7 HOLISTIC WELLNESS: SPORT, RECREATION, SEXUALITY AND SPIRITUALITY (G)

Overall facilitator: *KC Khumalo, Hillary Lane*

SESSION 1: KEYNOTE SESSION

Chair:

Jason Bantjes

14:00 – 14:10

Welcome remarks and outline of the programme

14:10 – 14:30

Key note address: *Hillary Lane*: The Finishing of the New York Marathon-A further Attest to our Abilities

14:30 - 14:40

Keynote responses

Session 2:

Sports

Chair:

Tecla Mlambo

14:40 – 14:55

Andrew Saukani: Perception and Level of Participation of Disabled Learner's in Sporting Activities in Selected Schools in Mangochi District of Malawi

14:55 – 15:10

Jason Bantjes, Leslie Swartz, Lauren Conchar and Wayne Derman: Promoting Participation in Sport: Perceptions Expressed by a group of South African Adolescents With Cerebral Palsy

15:10 – 15:25

Anthea Brinkman: Qualitative Evaluation of Special Olympics Healthy Communities Programmes Internationally

15:25 – 15:40

Khumalo K.C. and Van Heerden H.J.: Status of Sport and Recreation Participation in A group of Youth in a school for Disability

15:40 – 15:55

Jason Bantjes, Leslie Swartz, Lauren Conchar and Wayne Derman: “There is soccer but we have to watch”: Why inclusive education in South Africa may Impede Participation in Physical Activity for Children with Cerebral Palsy

15:55 – 16:10

Questions and responses to the 5 presentations

16:10 – 16:20

Picking-up a cup of tea

Session 3:

Recreation, sexuality and spirituality

Chair:

Hillary Lane

16:20 – 16:35

Action Amos: Towards a disability Law in Malawi

16:35 – 16:50

A.Rhoda, C.De Wet, R.Felix, C.Goliath, C.Joseph, M.Kloppe, H.lienbenberg and G. Mji: Methodological steps used to Evaluate the Alignment of Rehabilitation Services in the Western Cape with relevant Policies

16:50-17:05

Frances Emily Owusu-Ansah: Sharing in the Life of the Person with Disability: Caregivers' Perspective

17:05-17:20

Questions and responses to the 4 presentations

Session 4:

Chair:

17:20 – 17:50

17:50 - 18:30

COMMISSION DISCUSSION, RESOLUTIONS, RECOMMENDATIONS & AND WAY FORWARD

K.C. Khumalo

Feedback & summary of key issues from the presentations - Rapporteurs

Prioritizing, action plans, resolutions, recommendations & and way forward commission chairs to report the following day

Hillary Lane



Born with Cerebral Palsy, I did not walk until I was 5 years old. I have been fortunate to have parents who led by example and never let me give up. Primary education was in South Africa and because of my hand control was a challenge and meant using a typewriter from grade 1. High School was in the UK, and future studies were not possible then because of my hand writing. Marriage and two children put me on another life track. However much time was spent assisting there people with disabilities both in the UK and South Africa, particularly in teaching computers to blind people and being the CEO of the Western Cape Cerebral Palsy Ass., for nearly six years. I now work at Afrinead – a project of Stellenbosch University, and run a project for Shonaquip – Clothes to cash exchange.

ABSTRACTS IN ORDER OF PRESENTATION

1. The Finishing of the New York Marathon – A Further Attest to our Abilities

Hillary Lane

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In 2011 I was approached to ‘run’ the New York Marathon. My reaction was to laugh, as I have Cerebral Palsy, and use a disabled parking sticker on my car so that I do not have to walk further than necessary. But then it got me thinking about what it would take to ‘run’ the New York Marathon, and even if I wanted to attempt it, how would I go about it? After thinking and talking about it I decided to attempt it as a ‘research’ into the effects on the body of a person with Cerebral Palsy. Once I had made up my mind, many possibilities came both from the scientific world and as well as friends and family to give the necessary help, and the support I received was staggering! This paper outlines the necessary preparatory steps I took to be able to cross the finishing line.

Key words: *Cerebral palsy, marathon, disability, sport*

2. Perception and Level of Participation of Disabled Learner’s in Sporting Activities in Selected Schools in Mangochi District of Malawi

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General negative perception that children born with physical disabilities are a burden to able bodied children, should be discarded as the latter are keen to associate and help them in many activities during the formative stages of life. It is, however, unfortunate that some disabled youth develop a self-inferiority status by withdrawing themselves from others and becoming isolatory and hostile. This study aimed at assessing the perception and levels of participation of learners with disability in sporting activities conducted in 12 primary schools and 6 kindergarten establishments in Mangochi, Malawi, as part of enhancing sports among learners with disability project. During the study it emerged that it is challenging for disabled children to engage in more rigorous sport undertakings like football with their able bodied counterparts. From the focus group discussions, observations, dialogue session with disabled and able bodied learners, it can be ascertained that inclusion of learners with disability in sporting activities would help erase *an idle minds, devils workshop mentality* as it would deter them from being in a mood of conceiving negative ideas or opinions which attracts them unflavored labels as being unfriendly, docile or difficult people in society. In this case, it is imperative that soft kind of sporting games like table tennis, pool and chess tables among others are made available to the inclusion of both able bodied and disabled learners and that the inclusion process is extended to the vocational education institutions.

Key words; *physical disability, formative stages, sporting activities, inclusion, intelligent*

3. Promoting Participation in Sport: Perceptions Expressed by a Group of South African Adolescents with Cerebral Palsy

Jason Bantjes, Leslie Swartz, Lauren Conchar, and Wayne Derman

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In spite of the health and psycho-social benefits of sport, adolescents with disabilities in developing countries frequently have limited access to sporting opportunities. The objectives of this study are to understand what a group of South African adolescents with cerebral palsy perceive to be necessary components of programs in order to promote participation in sport and exercise programmes. We conducted in-depth interviews with 15 adolescents with Cerebral Palsy living in South Africa. Data was analysed using Interpretive Phenomenological Analysis. The results suggest that programs should allow participants to exercise choice and socialize while also providing physical challenges, emotional stimulation and coaching. Programs should allow participants to experience mastery, demonstrate their capabilities, participate in competition and win prizes. The participants also articulate a desire for equality, fairness and inclusivity to be integral components of sports programmes for adolescents with disabilities. More work is required to validate the findings of this study and to investigate how they might be incorporated into sports programmes to promote participation among adolescents with disabilities living in resource scarce environments.

Key words: *disability; sport; physical activity; adolescents.*

4. Qualitative Evaluation of Special Olympics Healthy Communities Programmes Internationally

Anthea Brink and Judith McKenzie

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Background: Healthy communities' programmes are being piloted in 14 locations globally collaboratively with Special Olympics International (SOI). The aim of these pilots is to develop, plan, implement and evaluate programming models to enhance the health and wellbeing of athletes (people with intellectual disabilities - ID) and, indirectly all those with ID. Furthermore these programs aim to improve the health of people with ID through education targeted at the person and family carers and by promoting the use of local community health services through education initiatives with health professionals and community personnel. The authors of this paper have been requested to evaluate how the healthy community programs can bring about improved health and healthier lifestyles for persons with ID in low and middle-income countries. The objectives of this paper are to review existing literature on health of people with ID in low to middle income countries and to compare this with the activities of healthy communities in two sites in Malawi and South Africa. A systematic review of literature and document analysis were conducted to answer the objectives of this evaluation. The literature review identifies critical issues in the health of people with ID. The document analysis highlights a range of activities that SOI healthy communities is facilitating aimed at improving health and wellbeing of people with intellectual disabilities. The literature review and document analysis justify and provide useful guidance for further research to be done on how the health needs of people with intellectual disabilities.

Key words: *Intellectual disability, prevalence of ID, common causes of death, access to health services, attitudes of professionals, public attitudes of ID, health and wellbeing, health promotion strategies.*

5. Status of Sport and Recreation Participation in a Group of Youth in a School for Disability

Khumalo K.C., and van Heerden, H.J.

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People with disabilities often feel that they are not really accepted as members of community groups in terms of their ability to become actively engaged in group activities. A questionnaire and focus group survey were conducted among 30 learners from different disabilities (learners randomly selected according to their disability e.g. spina bifida 7%) in R.P.Moodley Special School. The respondents consisted of 37% females and 63% males. Results indicate that while all scholars participated in sport and recreation in the school-setting, only 7% did so in their communities because of lack of recreational and sport facilities. The preferred sport activities were hockey, swimming, baseball and golf but most participated in soccer (28%), tennis (20%), basketball and table tennis (16%), athletics, cycling and cricket (4%). With respect to leisure activities, the majority watched television (50%); listened to the radio (20%) play sport (13%), read books (10%) and visited family (7%). The group indicated they were obliged to watch different sport and recreation programmes on television instead of participating in their communities. The study reveals that disabled scholars did not generally participate in sport and recreation activities within community settings and highlights, the need for better equipment/facilities, and development of programmes within their communities with the support of the Department of Sport and Recreation.

Key words: *status, sport, recreation, youth, leisure.*

6. “There is soccer but we have to watch”: Why inclusive education in South Africa may Impede Participation in Physical Activity for Children with Cerebral Palsy

Jason Bantjes, Leslie Swartz, Lauren Conchar, and Wayne Derman

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Inclusive educational practices and policy have had a significant impact on the role, position and composition of special needs schools for children with disabilities in South Africa (SA). One unanticipated consequence of this is the impact it has had on the co-curricular and sports programme in special needs schools and on the level of participation in physical activity among children with cerebral palsy. The objective of this study is to explore the lived experiences of children with cerebral palsy and their involvement in physical activity. This ethnographic research, conducted in a special needs school in SA, consisted of observations of the practices within the school and semi-structured interviews with member of staff and pupils in the school. Data was analysed using Interpretive Phenomenological Analysis. The study confirms the findings of previous research which shows that the level of participation in physical activity is mediated by a number of psycho-social and physiological factors. However, unlike other research, this study shows that inclusive educational practices can impede involvement in sport and can act as a significant barrier to participation in physical activity for children with motor impairments because of resource limitations and the way sport is organized in SA schools for historic reasons. More research is required, particularly within an action research paradigm, to understand what interventions can be implemented within schools to promote participation in physical activity among children with disabilities in resources scarce

environemnts.

Key words: *disability; sport; physical activity; inclusive education; South Africa.*

7. Wheelchair User Satisfaction and Functioning: Pre and Post Comprehensive Mobility Support Project (CMSP) in Zimbabwe

Tecla Mlambo, Clement Nhunzvi, Elsje Scheffler and Deborah Tigere

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Introduction: Personal mobility is a precondition for enjoying human rights and living in dignity (WHO, 2008). An appropriate, well designed and well-fitted wheelchair is a first step towards inclusion and participation in society. CMSP was introduced to improve wheelchair service delivery in Zimbabwe and was delivered according to the eight steps promoted by the WHO Wheelchair services Guidelines. The objective of this study is to assess user satisfaction and functioning, prior and post wheelchair service delivery. A descriptive study was done with 124 wheelchair users in the CMSP. Adapted standard questionnaires on user satisfaction and functioning with a wheelchair, two focus group discussions and two case studies were used to collect data. Data were analysed quantitatively and qualitatively. The majority of the wheelchair users were under 20 years of age, used public transport (74%) and had received their pre CMSP wheelchair as a donation without a service (90%). The most common condition was cerebral palsy (55%). About 30% reported having complications and the most common type reported were contractures. Adults and children differed in their perceptions of what aspects of wheelchair and service were considered most important with children prioritizing size, manoeuvrability, meeting user's needs and ease of use while adults considered durability, safety, ease of use, comfort and follow-up services as most important. User satisfaction with the pre CMSP wheelchair and service were significantly lower than with post CMSP wheelchair and service ($P < 0.001$). Function significantly improved with the CMSP wheelchair ($p < 0.001$). Comprehensive wheelchair services delivered according to WHO guidelines resulted in increased user satisfaction and function.

Key words: *wheelchair user, satisfaction, functioning, service, Zimbabwe*

8. Towards a Disability Law in Malawi

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The purpose of this study is to examine the processes and challenges contained in establishing a disability law in Malawi from a Disabled Person perspective. The study of disability is experiencing significant changes which have affected all of the social sciences, but relatively little attention has been devoted to this subject of process required to establish a disability law. The study examines the challenges of DPOs in advocating for a law in Malawi and how these were overcome. Perhaps the major obstacle to the analysis of disability policy is the lack of a general consensus about the nature or meaning of disability. In fact, at least three distinct definitions have been used in the formulation of government plans and programs for disabled persons in Malawi. 1) Economic Definition 2) Medical Definition and 3) Social-Political Definition. The lack of a clear definition on whether disability was a human rights/development issue decreases the progress in adopting the real understanding and appreciation of needing to assist persons with disabilities. Resistance to change and culture also contributed to the challenge that duty bearers had in accepting

disability as an agenda issue that required a law of its own. Lack of knowledge of legal implications of not having or a having a law among persons with disabilities/DPOs delays advocacy work. Ignorance on the cost implications by duty bearers also contributed to the delay of accepting disability as a priority that requires a law. Lack of political will is a major contribution factor in having or not having a law. This study has examined the normative and policy implications of three major definitions of disability, and it has assessed the contributions by stakeholder at national level and abroad bring in a new understanding about disability and unifying the voice of persons with disabilities. The study also highlight the steps taken to lobby and advocate for a disability law in Malawi despite the challenges.

9. Rehabilitation Services in the Western Cape with Relevant Policies

A. Rhoda, C. De Wet, R. Felix, C. Goliath, C. Joseph, M. Kloppe, H. Liebenberg, G. Mji, N. Mlenzana, S. Stathum
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The evaluation of service delivery systems is seen as a focus research area in rehabilitation and has been described as a systemic and continuous process of information provision for the purpose of determining the value of a programme. The aim of this presentation is to present the protocol for the process of developing methodological steps for the evaluation of institution based rehabilitation service model in four sites in the Western Cape. Mixed research methodologies were used focusing on the seven objectives of the NRP and the ability of the four sites to deliver what these objectives promised. This mixed research methods approach included Kaplan's framework of developing organizational capacity to evaluate the delivery of effective services, while the ICF framework was used to measure the outcomes of the clients receiving these services. Focus group discussions concentrated on: the capacity of the four sites as organizational structures to deliver rehabilitation services; and the reaching of the rehabilitation outcomes by the patients receiving the services as well as client satisfaction. As the seven objectives of the NRP linked to CBR and the UNCRPD, it was concluded that these will be used as yardsticks to evaluate the ability of the rehabilitation services in the four sites to deliver rehabilitation. Indicators were developed based on the seven objectives of the NRP, aspects from the CBR matrix and 5 health and rehabilitation articles from the UNCRPD. Fulfillment of these indicators by the four sites would give the sites the capacity to deliver rehabilitation services based on the organizational framework by Kaplan. Validated rehabilitation outcome measures underpinned by the domains of the ICF were selected to assess clients before and after receiving rehabilitation. Development of the methodology for evaluation of rehabilitation sites was based on international and local policies and guidelines.

Key words: *Rehabilitation sites, Evaluation, National Rehabilitation Policy, Methodology*

10. Sharing in the Life of the Person with Disability: Caregivers' Perspective

Frances Emily Owusu-Ansah
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Disability comes in many forms. Ageing, with its age-related complications, is a form of disability. This thought paper examines some of the challenges and issues in care giving for the aged who is also disabled through the presentation and discussion of clinical cases laced with the lived experiences of the author as a caregiver and clinician. In the present Ghanaian society it appears that care for the aged who are disabled is compounded by the rapid migration of many Ghanaians to 'greener pastures' in search of a brighter future with consequent empty homesteads and

fragmentation of the socio-cultural norms that hitherto provided care for the aged. In the absence of well-established professional care facilities informal care giving, with its challenges, has become the norm for many. The paper posits that self-care is the most important, and yet often forgotten, aspect of informal care giving. When this is neglected, caregiver burnout is sure. The result is poor physical, mental, and emotional health for the caregiver. In this state a caregiver may do more damage to self and the care-recipient. The paper concludes with recommendations for caregiver self-care.

Key words: *disability, caregiver, Ghana*

9.8 RESEARCH EVIDENCE AND UTILIZATION (H)

Overall facilitator: Leslie Swartz & Tsitsi Chataika

SESSION 1: KEYNOTE SESSION

Chair: *Tsitsi Chataika*

14:00 – 14:10 Welcome remarks and outline of the programme

14:10 – 14:30 *Key note address:* Rebecca Matter: Scoping Reviews to Inform WHO Health-related Rehabilitation Guidelines

14:30 - 14:40 Keynote responses

Session 2: Research Evidence and Utilization

Chair: *Jonathan Makuwira*

14:40 – 14:55 *Sylvia Palisa Thawani:* CBR Stories from Malawi: Case studies from MACOHA CBR Programme

14:55 – 15:10 *Lynn Cockburn, Shaun Cleaver and Ezekiel Benuh:* Considerations about researching Disability prevalence in Africa: an example from Cameroon

15:10 – 15:25 *Marcia Lyner-Cleophas:* Disability inclusion and exclusion at Stellenbosch University Through the lens of staff that support students with disabilities: preliminary findings

15:25 – 15:40 *Rochelle Holm and Chrissy Zimba:* How do Malawian's disability act, water act and Sanitation policy merge to a solution?

15:40 – 15:55 *Tsitsi Chataika and Patrick Ngandini:* Language as a Mirror of the Mind: A Linguistic Analysis of Marginalisation of Disabled People and a Quest for Enabling Language in Zimbabwe

15:55 – 16:10 **Questions and responses to the 5 presentations**

16:10 – 16:20 **Picking-up a cup of tea**

Session 3: Research Evidence and Utilization

Chair: *Sylvia Palisa Thawani*

16:20 – 16:35 *Edward Mupotola, Jenny Schaanning and Alick Nyirenda:* Pathways to Mainstreaming Intellectual Disabilities: A study on Intellectual Disabilities in Southern Zambia

16:35 – 16:50 *Brian Watermeyer:* Psychoanalysis, Race and Disability in the Global South: Problems and Possibilities

16:50 – 17:05 *Jonathan Makuwira:* Spectatorship of Suffering and the Commodification of Disability in Malawi: Issues and Perspectives for Disability-Inclusive Development

17:05 – 17:20 *Ingrid Van Der Heijden:* What Works to Prevent Violence against Women with Disabilities An Evidence Brief

17:20-17:35 *Action Amos and Lorraine Wapling:* Epilepsy in Malawi

17:35-17:50 **Questions and responses to the 5 presentations**

Session 4: COMMISSION DISCUSSION, RESOLUTIONS, RECOMMENDATIONS & AND WAY FORWARD

Chair: ***Leslie Swartz***

17:50 – 18:10 Feedback & summary of key issues from the presentations - Rapporteurs

18:10 - 18:30 Prioritizing, action plans, resolutions, recommendations & and way forward commission chairs to report the following day

Rebecca Matter



Rebecca Matter directs the International Program on Disability, Technology and Rehabilitation within the Department of Rehabilitation Medicine at the University of Washington (UW); and serves as a researcher and program evaluator for the UW Center on Technology and Disability Studies. Current responsibilities also include managing knowledge translation activities for the Americans with Disabilities Act Knowledge Translation Center, and conducting systematic reviews to inform clinical guidelines for the Paralyzed Veterans of America. Within the international field, Rebecca has organized two workshops at UW that address disability, rehabilitation and technology within low and middle income countries; conducted research on the provision of wheelchairs in Zimbabwe and Namibia; taught a UW study abroad course in Brazil entitled *Disability in Low Resourced Environments*; and recently completed evidence reviews for the World Health Organization to inform the *WHO Health-Related Rehabilitation Guidelines*. Her presentation at AfriNEAD will cover evidence reviews conducted on assistive technology and rehabilitation services in resource limited environments. Rebecca holds a Masters in Public Policy from the University of Minnesota and is beginning a doctoral program in Public Health at the University of Cape Town.

ABSTRACTS IN ORDER OF PRESENTATION

1. Scoping Reviews to Inform WHO Health-related Rehabilitation Guidelines

Rebecca Matter

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Two scoping reviews were conducted in 2013-14 by the University of Washington as part of larger evidence reviews to inform the development of the World Health Organization (WHO) Guidelines on Health-Related Rehabilitation. The WHO Guidelines intend to inform decision makers (e.g., ministries of health) on how to strengthen rehabilitation services within health systems in less resourced settings. I served as the project director for both scoping reviews. The two scoping reviews we completed addressed the topic areas of **Assistive Technology (AT)** and **Service Delivery** within resource limited settings. The aim of each scoping review was to identify and characterize the extent, range and nature of existing peer-reviewed evidence. Each scoping review involved a literature search of academic databases, screening based on predefined inclusion/exclusion criteria, data extraction, and thematic and numeric analysis. Searches targeted resourced limited settings (low-middle income countries and/or underserved populations), all types of disabilities, all ages, and were limited to publication year 2000 through 2013. The majority of included studies in the both scoping reviews had lower quality research designs, and addressed a broad range of health systems themes such as effective service models and barriers to accessing products and services. The Service Delivery scoping review captured a range of service models such as home-based care, tele-rehabilitation and self-management. The most frequent AT types addressed by included studies were spectacles, prosthetics, and hearing aids. In conclusion, a number of research gaps were identified (topics, quality level, populations) as well as the overall lack of system-level research needed to guide policy and policy implementation. Where higher quality research existed, specific models were recommended for building capacity of AT and Service Delivery within health systems.

Key words: *scoping review, evidence review, rehabilitation services, assistive technology, health systems*

2. CBR Stories from Malawi: Case studies from MACOHA CBR programme

Sylvia Palisa Thawani

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CBR stories from Malawi encompass case studies derived from the Community Based Rehabilitation activities being implemented by the Malawi Council for the Handicapped. Community Based Rehabilitation (CBR) is a strategy for equalization of opportunities for persons with disabilities. The Malawi CBR programme conforms to WHO CBR Guidelines comprising of Health, Education, Livelihood, Social and Empowerment components. The case studies were collected through interviews and focus group discussions from CBR districts across Malawi in the five components. The health component showcases cases of Bertha Sadiki and Joseph Adiasi from Blantyre and Ntcheu CBR respectively. Bertha is a child with albinism who takes advice and counseling and Adiasi received a tricycle through the CBR programme. Further, on education, Nyozeni Yusuf from Blantyre CBR benefited from education sponsorship and mobility aid. On livelihood, Grayton Muso was able to access loans from MARDEF and is able to sustain himself after he started his own business and of Knip White who was trained and resettled by MACOHA in

Blantyre CBR. There are two articles that feature self-help groups and fall under the social and empowerment component. The two self-help groups; Ndemanje irrigation scheme and Takondwa Disability self-help group have persons with disabilities that enhance social inclusion, self-reliance and disability support and training. CBR stories from Malawi provide concrete evidence of positive results and outcomes that can emanate from active involvement and participation of persons with disabilities, their families and communities. Each story briefly presents the social economic situation of a person with a disability (ies) prior to involvement in a CBR program, intervention that an individual benefitted from through CBR and finally, positive results in the form of outcomes and impact after the intervention.

Key words: *community based rehabilitation, rehabilitation and World Health Organization.*

3. Considerations about researching disability prevalence in Africa: an example from Cameroon

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This project addresses the implications of the lack of disability prevalence data, in addition to evaluating the lessons learned through investigating the prevalence of impairments and disabilities, in Cameroon. Disability prevalence data is vital to effectively addressing disabling barriers and creating a more inclusive environment for people living with disabilities. However, disability prevalence data is highly complex and the collection of accurate data is complicated by the varied perceptions of disability. A multi-stage cluster design was used, and included urban, semi-urban and rural areas. In the first stage, the team screened 3,933 households, representing an estimated screening sample of 18, 878 individuals. In the second stage, structured interviews were conducted. The interviews included the International Classification of Functioning, Disability and Health (ICF) Checklist to confirm disability status and determine the nature of disability. A total of 1,233 individuals screened positive for having a disability. According to this study's cluster design the prevalence of screening positive for disability in this region was 6.9% (95% CLs 5.7-8.2%) and the population prevalence of disability was 6.2% (95% CLs 5.2-7.2%). Of the individuals who screened positive for disability, 1,106 (89.7%) of them had a participation restriction or activity limitation which was of moderate severity or greater, suggesting that the screening tool was useful for identifying many persons living with moderate or severe disability but not very sensitive at identifying people with minor disabilities. The study indicated that a significant proportion of individuals are living with impairments or disabilities in Cameroon and these results can be used to justify the need for, and inform the design of, programming for individuals with disabilities in this region.

Keywords: *Cameroon; prevalence; international classification of functioning, disability, and health.*

4. Disability inclusion and exclusion at Stellenbosch University through the lens of staff that support students with disabilities: preliminary findings

By Marcia Lyner-Cleophas

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Increasingly, disability support at Stellenbosch University (SU) is widening as more students enter higher education in South Africa (SA). SU has 366 (SISS 2014) students who indicated a disability out of roughly 28 500 students (approximately 0.13 of total). This has implications for the

university and staff campus-wide. I was interested to scientifically explore the experiences of staff across SU involved in support to students with disabilities. The White Paper on Post-School Education and Training (2013) in SA encourages research in disability in higher education. The necessary institutional ethical clearances were obtained. Non-probability sampling was done. As the research progressed, use was made of snowball sampling to widen exploration of staff experiences. The full study was a mixed methods study. In this presentation I only present the findings of 27 staff interviews that formed part of the qualitative method that sought to establish the authentic voice of support- and academic staff campus-wide. An external interviewer conducted the research to promote objectivity and free expression and add credibility to the research. Discourse- and constant comparative analysis was used to code and analyse data. The preliminary findings of the staff interviews included the significance of collaborating across the university; the mixed staff feelings and thoughts regarding students with disability.

Key words: *staff experiences; disability inclusion; Stellenbosch University*

5. How do Malawian's disability act, water act and sanitation policy merge to a solution?

Rochelle Holm & Chrissy Zimba

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The need for improving water and sanitation is detailed in Millennium Development Goal (MDG) Target 7.C, which states: “Halve, by 2015, the proportion of the population without sustainable access to safe drinking water and basic sanitation.” Yet, it is important to recognize the economics of disabled persons may prevent them from improving their water and sanitation situation. The most common water and sanitation solutions may be too expensive for disabled people, who may have lower incomes. Mzuzu University Centre of Excellence in Water and Sanitation SMART Centre, supports activities to improve access to safe and clean water and improved sanitation with a focus for all people, including people with disabilities. This is achieved by the Mzuzu SMART Centre focusing on training local businesses that will produce and sell a range of new low cost water and sanitation solutions. One of the main goals of the SMART Centre is to establish a sustainable and compatible supply sector of options which can reduce costs of communal systems and that are affordable for (groups of) households. The Smart center trains local private sector in manual well drilling, rope pumps, groundwater recharge, water storage tanks, irrigation, water filters, latrines and other technologies. One of the examples of these latrines is the corbelled latrine, which costs about MK7000.00. This paper presents how Mzuzu University Centre of Excellence in Water and Sanitation, SMART Centre, is using low-cost water and sanitation approaches to achieve water and sanitation MDG solutions through a combination of guidance by the Malawian Disability Act, Water Act, and Sanitation policy.

Key words: *Disability, legislation, policy, water and sanitation, Malawi*

6. Language as a Mirror of the Mind: A Linguistic Analysis of Marginalisation of Disabled People and a Quest for Enabling Language in Zimbabwe

Tsitsi Chataika and Patrick Ngandini

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Noam Chomsky argues that language is a mirror of the mind in a deep and significant sense. Times have changed for disabled people... but language lags behind. This is despite the fact that language reflects how members of a social group evolve. Various words and concepts used to describe disability and disabled people all have their own histories and implications for disabled people. The use of outdated language and words to describe disabled people contributes greatly to perpetuating old stereotypes. No longer should we view disabled people as helpless or tragic victims. If public opinion about disabled people is to be brought up to date, the public needs to hear and learn to use appropriate language. It is against this background that we are conducting this qualitative study, informed by speakers of two main Zimbabwean indigenous languages; ChiShona and IsiNdebele, to ascertain the nature of language or terminology used on disabled people. We utilise participant observation, informal discussions and key informant interviews as data gathering techniques. The number of participants will be determined by reaching the level saturation. This is whereby the same information keeps on recurring from different participants to the extent that it becomes unnecessary to keep on collecting data. We intend to suggest enabling ChiShona and IsiNdebele descriptive words and language that can be used when talking to or about disabled people. We are however aware that if a new ‘politically correct’ language begins to take on the meaning of the word it replaces, then the game remains unchanged; hence the need for raising awareness.

Keywords: *language, terminology, disability, ChiShona, IsiNdebele, indigenous languages, disabled people*

7. Pathways to Mainstreaming Intellectual Disabilities: A Study on Intellectual Disabilities in Southern Zambia

Edward Mupotola, Jenny Schaanning, Alick Nyirenda

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The limited inclusion of Children with Intellectual Disabilities (CWIDs) in many CBR programmes is universal as documented by the WHO. This state of affairs was the rationale for undertaking this study. The key objective of the study was to: Identify and assess the specific needs and barriers of both boys and girls with disabilities, and their parents and guardians, in all aspects of life as identified by the CBR matrix in the WHO guidelines on CBR (WHO 2010). A 10 days in-depth, exploratory, qualitative study was conducted in the two districts of Kazungula and Livingstone by an interdisciplinary research team made up of 9 people from Zambia and Norway. The mobilisation of CWIDs and their families in the sample was conducted by the identified partners of the CBR programme in the two pilot CBR districts. The study mainly employed FGDs and Interviews. The study showed that there were an estimated 1,050 persons with intellectual disabilities in Kazungula and 1,277 in Livingstone – an estimated total of 2,327 persons with intellectual disabilities in the catchment area of this study though the actual number could have been higher. The study revealed barriers to participation and inclusion of CWID at the following levels: Barriers to inclusion in the family and in the community and barriers in access to livelihood, health and to education. The study also brought to the fore other related issues such as; Challenges faced by boys and girls with intellectual disabilities and parent support groups.

Key Words: *Intellectual disabilities, CBR Zambia, Parents Support Groups, Inclusion and CBR Matrix*

8. Psychoanalysis, race and disability in the global South: Problems and possibilities

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There is a long and rich tradition of psychoanalytic theorizing on the underpinnings of racism, suggesting what a shift toward reduced inequality may require. The relevance of psychoanalysis 1) to emancipatory social critique, and 2) to majority world contexts far removed from its cultural origins, is a matter of ongoing dispute. Some theorists have begun applying psychoanalytic race theory to disability inequality. This paper examines some of the possibilities and problems with this cross-application, in the context of issues specific to disability in developing nations. Conclusions are that, if mindfully approached, psychoanalytic race theory has much to offer our understanding of the stubborn reality of disability prejudice.

Key words: *Psychoanalysis, race, disability*

9. Spectatorship of Suffering and the Commodification of Disability in Malawi: Issues and Perspectives for Disability-Inclusive Development

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The parading of people with disability on the roads of Malawi's capital city, Lilongwe, has become a common occurrence. While it is understood that the persons with disability are indeed in need, and require financial and (often less) material support, the conduct raises ethical as well as moral issues both to the persons with disability (the helped) and the helper (non-disabled person). At the center of the matter are the 'spectatorship' of suffering and the 'commodification' of disability. The purpose of this paper is to spark a debate which will contribute to the ongoing debate about disability and inclusive development using Malawi as a case study. The paper's central thesis is that the interplay between the 'helper' and the 'helped' (person with disability) needs deconstructing in order to uncover the subtleties of power, relationship and exploitation. Further, the paper seeks to engage in a critical analysis of exogenous and endogenous representations of the commodification of disability and pity. The paper makes a furious case in highlighting structural failures on part of not only government but also disability people's organizations to take control of the matter and engage people with disabilities in a constructive and rehabilitative disability-inclusive development. The paper concludes by offering some policy-oriented recommendations on how to deal with the situation.

10. What Works to Prevent Violence against Women with Disabilities? An Evidence Brief

Ingrid van der Heijden

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Gender equality is a major internationally agreed upon development goal (the MDG 3 aims to promote gender equality and empower women). The WHO concludes that many MDG targets will be missed if violence against women – one of the most blatant manifestations of gender

inequality - is not addressed. Furthermore, the high social and economic costs of violence against women and girls are extremely relevant to development policy and also to efforts to reduce poverty and ensure sustainable development. Given that violence against women with disabilities is under-reported and under-researched and contributes to the invisibility of their victimization, this evidence brief presents key findings from the existing research on violence against women with disabilities and presents how these can be utilised to inform prevention interventions and response strategies. The findings are based on a literature review of development reports and research studies on the causes, nature and consequences of violence against women with disabilities, and evidence from existing prevention interventions. The brief reveals a lack of research done in poor to middle income countries. The risk factors reveal that women with disabilities have increased vulnerability to violence. Evidence from existing interventions on what works to prevent violence against women with disabilities is lacking. There is an urgent need for developing, testing and implementing effective interventions that address both violence against women and disability.

Key words: *Disability, women with disability, violence, South Africa*

11. Epilepsy in Malawi

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Prevalence, treatment gap, education and health support of people living with epilepsy in Balaka, Blantyre, Lilongwe, Ntcheu, Machinga, Mzuzu and Zomba which represent 38% of the total population of Malawi. The objectives of the study were to (i) document and analyse information on the treatment gap; (ii) determine the education levels of people with epilepsy and (iii) determine the gender distribution of people with epilepsy. Information was obtained from; a door- to- door cross-random sampling of 10230 inhabitants of 7 districts and a medical source through an audit. Outcomes: Treatment gap: 32%; Education: 61% of people with epilepsy illiterate; Females with Epilepsy: 45%; Males with Epilepsy: 55%; Most affected age: 6-18 47%; School going children: 46% not attending school. The above results reflect a combined study but a breakdown of each district was done. Comparison was also done on the urban and rural settings as well as regional breakdown representing North, Central and Southern Districts. There is also a wider variation between areas within the same district. This could be related to methodological problems, diagnostic gap and demographic dynamics. The care of epilepsy in Malawi by different institutions was sampled and audited to reflect the epilepsy care gap. Statistics used in this report cannot be extrapolated against the population of Malawi and taking into account cultural, environmental, social and other differences across various districts of Malawi.

Key words: *Epilepsy, care, Malawi*

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11.0 RECOMMENDATIONS OF THE 3RD AFRINEAD SMPOSIUM 2011:

a. **Children, and youth with disabilities**

Presenters from this theme highlighted the value of conducting needs assessment for children with disabilities in Africa. Where possible, children should be included and informed (informed consent and assent, as appropriate) in most of the decisions that affect them. At all-time and where possible, self- representation of children should be encouraged. A communication freeway between parents and service providers, as well as researchers and policy makers, should be developed. Capacity-building needs to be done across all levels; representatives from this theme saw the relationship between stakeholders including children with disabilities, being underpinned by principles of family centeredness.

b. **Education: early to tertiary**

This theme focused on three critical areas:

- **Educator training** (teachers and lecturers) with emphasis on curriculum adaptation and inclusive assessment, policy awareness, and paradigm shift from a focus only on Early Childhood Education to continuing higher/life-long learning.
- **Inclusion of disability issues in the curriculum across disciplines in higher education:** with training all future professionals, policy-makers and researchers in disability issues so that they can include disability at all levels, including the classroom
- **Responsive research:** defining a research agenda according to practical needs and best practice, children's and families' experiences, policy-led (implementation of policy), developing reliable database (and Knowledge Management Systems) and highlighting education as a gateway to success.

Three strategies were tabled to address the above and these were:

1. Following up on issues of discrimination and be able to explore ways of taking legal actions
2. Advocacy and lobbying - working with policymakers, DPO's and other relevant stakeholders
3. Writing four papers based on the above three key issues: this commission further selected people who should champion the writing of papers.

c. **Development Process in Africa: Politics, Poverty and Indigenous Knowledge Systems**

This theme highlighted issues of poverty and access as relevant for everyone in society but people with disabilities are more likely to be excluded. Evidence demonstrates a significant association between poverty and disability. When addressing needs for people with disabilities, there is a need to consider African methods of governance e.g. tribal authority and imbizo versus "modern" government's structures. However, traditional leaders must also be convinced that some of the cultural beliefs about people with disabilities are simply myths, stigmatising and disadvantaging those with disabilities.

There is a need for specifically designed advocacy programs targeting traditional leaders in rural areas to combat culture-based violent discrimination against people with disabilities. Health service providers need to understand the barriers that people with disabilities face if service delivery is to be equitable and inclusive. On the other hand people with disabilities should demand their health rights as enshrined in different statutes. AfriNEAD needs to extend to universities of other African countries. It should also have an annual entry within the African

Journal on Disability (AJOD) journal for its key activities.

DPOs should link with service providers and form networks with the law fraternity to look at policies and legal frameworks that will ensure inclusion of people with disabilities on policy development processes. AfriNEAD needs to work with research institutes and national bureau of statistics to make disability visible in monitoring of national development plans and the MDGs.

d. Economic Empowerment

This theme identified three recommendations:

- Urgent need for a paradigm shift from the traditional career guidance to career construction in the way persons with disabilities perceive lifelong career choices by utilising the concept of entrepreneurship.
- Need to decentralise the provision, design, repair and maintenance of assistive devices and empowering disabled people to be the custodians of this process through support from government and other stakeholders.
- Need for African governments to domesticate the UN Convention on the Rights of People with Disabilities to ensure the right to equal access to transportation, information, services and facilities. Equal access can be achieved through the engagement of professionals and experts in the development of legislation, access guidelines and operationalizing policy in making the environment accessible for all.

e. Health, HIV/AIDS, and Community-Based Rehabilitation

This theme also identified three recommendations:

- To build a critical mass within the mainstream of society on disability issues including mainstream human rights organisations e.g. Amnesty International, Human Rights Watch.
- To investigate the mismatch between policies and implementation; and to use this evidence with core quantitative data to advocate government.
- To motivate and lobby governments to adopt Community Based Rehabilitation as part of their National Rehabilitation Policy.

f. Holistic Wellness: Spirituality, Sport and recreation

The focus for this theme was improved accessibility to all support systems that will facilitate people with disabilities to engage in activities that enhance holistic wellness such as sport, recreation and spiritual related activities. Appropriate assistive devices e.g. wheelchair, prosthesis, orthotics, hearing aids as well as accessible transport is essential to achieve success in this theme. Disability is not necessarily a hindrance; it can illustrate to society how people can successfully cope with challenges. However, it is essential to improve public education on disability issues and adaptation, as well need for the development of human resources to support people with disabilities. In all of this it is important to understand the context and take into consideration indigenous knowledge systems including local and global issues.

g. Research Evidence and Utilisation

This theme highlighted three key issues:

- i. Evidence based practice requires a matching-up (or alignment) between research, participation and feedback from the community, for effective intervention and/or practice to flourish.

- ii. There is the need to recognize and value alternative forms of gathering information to complement rigorous scientific methodologies. There is a plethora of rich information that needs to be collected and structured for recognition by academic circles so that it too can inform policy and address identified gaps.
- iii. Once research is put into action – there needs to be on-going monitoring and evaluation to ensure that practice remains linked to evidence, informed by and appropriate to cultural setting, to promote continued effective outcomes.