Workshop Report

Strengthening Capacity for Disability Measurement across Africa

SADC Regional Disability and Statistics Meeting
Tuesday - Wednesday, 21 - 22 July 2015 University of Pretoria, Pretoria, South Africa

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Acronyms

ADA  Africa Disability Alliance
AU   African Union
CBM  Christoffel Blindernmission
CBR  Community-based rehabilitation
CEO  Chief Executive Officer
COPDAM Communities of Practice in Disability Advocacy for Mainstreaming
DHS  Demographic and Health Survey
DPOs Disabled people's organisations
DSD  Department of Social Development
EAP  Economic Active Population
ESSA Employment Service of SA
EU   European Union
GHS  General Household Survey
GovInn Centre for the Study of Governance Innovation
HBS  Household Budget Survey
HEMIS South African Higher Education Open Data
ICF  International Classification of Functioning, Disability and Health
ICM  Integrated Committee of Ministers
ILO  International Labour Organization
INDS Integrated National Disability Strategy
INSTAT Institut National de la Statistique
LFS  Labour Force Survey
LMIS Labour Market Information System
MACOHA Malawian Council for Handicapped
M & E Monitoring and Evaluation
MINPOP Ministère de la Population et des Affaires Sociales
NDP  National Development Plan
NDPOs National Disabled People’s Organizations
NSDS National Skills Development Strategy
OHSC Office of Health Standards of Compliance
PERSAL Personnel and Salary System
PFPH La Plateforme des Fédérations des Handicapés de Madagascar
PWD Persons with disabilities
SADC  Southern African Development Community
SGDs  Sustainable Development Goals
Stats SA  Statistics South Africa
UNCRPD  United Nations Convention on the Rights of Person with Disability
UNDP  United Nations Development Programme
UNICEF  United Nations Children’s Fund
UNPRPD  United Nations Partnership to Promote the Rights of Persons with Disabilities
WG  Washington Group
WHO  World Health Organisation
ZIMSTAT  Zimbabwe National Statistics Agency
1. Executive Summary

1.1. Workshop Overview

This workshop enhanced the understanding, planning and coordination of disability statistics by bringing together Bureaus of Statistics and Departments of Labour and Social Development, Disability Federations and other stakeholders from eight of the 15 member states of SADC. International organizations including Christoffel Blindenmission (CBM), the Delegation of the European Union (EU) in the Republic of South Africa, the International Labour Organization (ILO), the United Nations Children's Fund (UNICEF), and the United Nations Development Programme (UNDP) also attended the workshop. Together, the participants sought to identify key issues that hinder the collection of accurate statistics on persons with disabilities and began mapping next steps to increase their collaboration in addressing challenges faced by this important yet marginalized sector. The two-day participatory workshop included statements and keynote addresses, information sharing and planning.

The Africa Disability Alliance (ADA) in conjunction with the Centre for the Study of Governance Innovation (GovInn) with financial support from the EU initiated this workshop in order to build shared understanding among regional government statistics departments as well as disabled people’s organisations (DPOs) of the challenges faced by persons with disabilities and to develop a roadmap of strategies to address these challenges through inclusive data collection mechanisms. In addition to sharing experiences and practices, the workshop created a platform for the statistical offices and disabled people’s organisations to discuss broader coordination and collaboration issues.

Day One was targeted at sharing of countries’ experiences, key outcomes, challenges and lessons regarding disability statistics. Outcomes of Day One included:

- Broader understanding of the efforts of each SADC country that participated in the workshop in collecting disability statistics and challenges faced.
- Understanding and appreciation of the European Union's obligations towards disabilities particularly in the area of funding and training for special needs teachers.
- Appreciation of the work and contribution of CBM towards disabilities in the area of funding and training.
- Shared experiences of efforts, progress made as well as the challenges that respective
countries in the SADC region face in ensuring that persons with disability are accurately represented and their rights respected through data collection measures.

- Learning that some countries in the SADC have strengthened efforts and built capacities of persons with disabilities in undertaking research and analysing research data for policy.
- Understanding of the ILO’s longstanding commitment to promoting social justice and achieving decent work for people with disabilities as well as the organisation’s efforts in promoting decent work for women and men with disabilities and work towards overcoming the obstacles preventing people with disabilities from full participation in the labour markets.
- A practical understanding of the challenges faced by teachers of and learners with disabilities as a consequence of the absence of accurate disability statistics and knowledge of the status of persons with disabilities.
- Understanding of the work and efforts of the UNDP in developing the capacities of national stakeholders including governments and organizations of persons with disabilities for the effective implementation of the Convention on the Rights of Persons with Disabilities (UNCRPD) by promoting disability-inclusive internationally agreed development goals.
- Understanding of the work in progress at UNICEF, in partnership with the Washington Group on Disability Statistics, towards developing a new survey module on child functioning and disability in an effort to address the need for comparable and reliable data on children with disabilities.

On Day Two of the workshop participants explored the ways in which disability statistics can be enhanced to contribute to achieving equal employment opportunities for persons with disabilities.

Day Two outcomes included:

- Understanding of the general status of persons with disabilities indicating the higher levels of unemployment among such persons and poor working conditions for those that are employed as well as the overrepresentation of persons with disabilities in the informal economy.
- Appreciation of the complexity associated with challenges relating to employment statistics of persons with disabilities due to the use of different definitions and measurements of disability between countries.
• Understanding of the work of the Washington Group to overcome the complex challenge of measuring disability across countries and establish uniform and comparable measurements.

• Understanding of the fact that strengthening the data collection for labour statistics including disability statistics was identified as a priority in a number of key meetings and forums on Africa (involving the African Union, regional and international organizations) as well as the Sustainable Development Goals (SGDs).

• Proposals and recommendations to national governments, the SADC secretariat, Cooperating Partners and Funding Agencies, National Disability Associations/Organizations on improving disability statistics and the plight of the disability sector and persons with disabilities and thereby create an enabled environment for the sector to operate effectively.

• Renewed interest in coordination and collaboration at country and regional levels among the member countries of the SADC, disabled people’s organizations and other stakeholders that participated in the workshop.

• Understanding of existing initiatives in member countries of the SADC for obtaining information regarding persons with disabilities especially in the health, education, employment and social protection sectors.

• Concrete country action plans and recommendations to obtain better disability related statistics especially in the sectors of health, education, employment and social protection.

• Commitments from individual participants, disabled people’s organizations and government bureaus of statistics to take concrete action and utilize the Washington Group module to improve disability statistics.

Participants worked together, discussing and exploring this extremely challenging but important programme area. With a spirit of collaboration, participants agreed that this work is indeed critical for planning, but can be addressed when they work together.

1.2. Disability statistics in Southern Africa, Commitment and Way Forward

At the closing of the workshop, participants agreed to advocate for the integration of disability and the inclusion of the disability module in national data collection exercises such as the census, labour force survey, demographic and health survey, etc. The participants further encouraged
countries that had already conducted or had disability surveys planned for the near future to utilize the data collected in such surveys.

Key messages to be carried forward include:

- The need for better governance and coordination of disability agendas
- Comprehensive data on disabilities and related issues
- Ensure disability (policy) mainstreaming in/across all government departments
- Elaborate action plans for implementing disability and related recommendations
- Training on disability data collection modules
- Training of teachers in/on disabilities
- Building the capacities of persons with disabilities and equipping them with skills to take up positions and be actively involved in statistics and data collection bureaus in their countries
- Building the capacities of national statistics bureaus to handle disability statistics
- Domesticate international decisions and recommendations on disability
- Promote the conduct of specialized surveys on disabilities, for countries that do not yet have such exercises in place

2. Background and Context

2.1. Background

2.1.1 Statistics in Southern Africa

Statistics in countries play a key role in providing reliable data to support disability mainstreaming, implementation of programmes and resource allocation. This is relevant especially because persons with disabilities remain amongst the most marginalized in most societies in southern African countries. Statistics that capture and are representative of persons with disabilities would ensure that such persons are not excluded from the development process in such countries.

2.1.2 Challenges facing persons with disability

Some of the specific challenges depicted by studies leading to the marginalization of persons with disabilities and lack of a proper understanding of the conditions of such persons include:

- The definition of disability with respect to national surveys and censuses which results in
low national prevalence rate for disability.

- Lack of disability mainstreaming among institutions.
- Lack of comprehensive baseline or benchmark data to assist in determining progress on disabilities and related issues.
- Lack of comprehensive data on children with disabilities
- Lack of or limited financial resources.
- Over reporting in cases of multiple disabilities where an individual with more than one disability may be counted in each listed category of disability.
- Under reporting, as disability is understood differently by different people. What one respondent may consider a disability may not be seen as such by another.

2.1.3 The Regional Policy Instruments Dealing with Disability

At the regional level, no Southern African Development Community (SADC) legislation currently exists in the form of a protocol that is exclusively dedicated to addressing the challenges which persons with disabilities face or to afford such persons the rights protected in the UNCRPD. The closest that the SADC region comes to providing an atmosphere in which the rights and interests of persons with disabilities are mainstreamed in SADC developmental programmes is in protocols dedicated to other spheres such as gender and health. For example, Article 9 of the 2008 SADC Protocol on Gender and Development states that, “the State Parties shall, in accordance with the SADC Protocol on Health and other regional and international instruments relating to the protection and welfare of people with disabilities in which Member States are party, adopt legislation and related measures to protect persons with disabilities that take into account their particular vulnerabilities.” Similarly, Article 15 (on Disabilities) of the 1999 Protocol on Health in the SADC states that the “States Parties shall cooperate and assist one another to a) promote effective measures to prevent and manage disabilities; b) increase access to improved technology related to assistive devices, and the creation of a barrier free environment for the equalisation of opportunities for persons with disabilities; and c) promote community-based rehabilitation programmes.”

2.2. Workshop Background: Africa Disability Alliance, COPDAM and Disability Statistics

The Africa Disability Alliance (ADA) is a technical agency that has created a credible niche in the
disability programming and policy implementation processes by working in partnership with the African Union (AU), African Governments, Civil Society and Continental/Regional and National Disabled People’s Organizations (NDPOs) in Africa. ADA is implementing a three-year programme with financial support from the European Union (EU) and Christoffel Blindermmission (CBM) entitled Communities of Practice in Disability Advocacy for Mainstreaming (COPDAM). COPDAM is a continental disability policy implementation strategy that is aimed at building the capacity of national and regional disability federations to negotiate and advocate for disability mainstreaming in all sectors of government and at the level of the AU. The programme has been implemented in six member states of the SADC namely, Lesotho, Madagascar, Malawi, South Africa, Zambia and Zimbabwe since January 2013.

However, all the Southern African countries are signatories to the UNCRPD. Article 31 of the UNCRPD requires State Parties to collect appropriate information, including statistical and research, to enable them to formulate and implement policies to promote, protect and fulfill the rights of persons with disabilities. Bureaus of statistics in countries that have ratified the convention play a key role in providing reliable data to support disability mainstreaming, implementation of programmes and resource allocation that ensures that persons with disabilities are not excluded from the development process. Therefore, the countries that have ratified the convention need to collect data on populations with disabilities for the implementation and monitoring of the UN convention. However, measuring disability represents a complex process. The complexity of the concept has resulted in the proliferation of statistics that are neither comparable nor easy to interpret.

The need for comparable population-based measures of disability for use by individual countries and international comparisons was recognized at the June 2001 UN International Seminar on the Measurement of Disability. The recognition was based on the scarcity and poor quality of data on disability, especially in developing countries, as well as the lack of internationally comparable measures (even among developed countries).

Regarding comparable measures, the Washington Group on Disability Statistics has worked to provide internationally comparable data within the framework of the International Classification of Functioning, Disability and Health (ICF) Model that aims to fulfill the stipulated requirement to monitor the UNCRPD.

Despite the progress that some countries in the SADC region have made on incorporating disability
and using the ICF framework and related questions into national censuses and surveys, the inadequacy of data on disability in many of the Southern African countries still persists. Additionally, the cost of disability in many of the SADC countries is generally unknown. A persisting lack of reliable and adequate data will continue to hamper progress in developing strategies, programmes and policies that can improve the wellbeing of persons with disabilities in the Southern African region.

The World Health Organization (WHO) established key recommendations for addressing the challenges of disabilities in the SADC region which include adopting the ICF framework, improving national disability statistics, improving the comparability of the data in the SADC region and developing appropriate tools to fill the research gaps (WHO 2011, World Report on Disability).

2.2.3 Facilitation and workshop design

Faced with the foregoing challenges, the Africa Disability Alliance collaborated with the Centre for the Study of Governance Innovation (GovInn) at the University of Pretoria and the UNESCO-UNU Chair on Regional Integration, Migration and Free Movement of People, hosted at GovInn, to facilitate the SADC Regional Disability and Statistics Meeting. The facilitator worked with ADA and GovInn management teams to plan and prepare this workshop. Workshop objectives, agenda, content, resource materials, and co-facilitation were discussed and developed in collaboration with the GovInn logistics management team.

Participants were selected and invited by ADA and GovInn. Participants represented Governments from the SADC region, civil society organizations and funding agencies. The workshop ran over two days and consisted of plenary and breakaway group discussions. All delegates were requested and encouraged to participate fully, accommodate each other’s opinions and contributions. While the main deliberations were conducted in English, translation to French for participants from Madagascar was also available.

3. Workshop Purpose, Objectives and Expected Outcomes

3.1. Purposes

The COPDAM disability and statistics regional meeting sought to address some of the highlighted challenges in the SADC region and to provide a platform for the region to share best practices on disability statistics and the development of expertise in methodologies of measurement of
populations with disability.

The meeting also sought to benefit from ILO expertise in exploring ways in which statistics and research could enhance equal employment opportunities for persons with disabilities. It was hoped that the ILO’s model on the use of statistics and research in the labour and employment sector could later be adapted or replicated in other sectors of government in the SADC region.

3.2. Objectives and Expected Outcomes

3.2.1 Objectives of the Workshop

The objectives of the workshop were:

1. To share country experiences and good practice in the collection and utilization of statistical information
2. To explore ways on how research and statistics in the SADC region can be utilized to the best interest of people with disabilities especially in achieving equal employment opportunities for persons with disabilities (ILO)
3. To identify key indicators related to labor and employment of people with disabilities
4. To provide a platform and create linkages for networking among countries and in the region.
5. To provide a basis for the establishment of a regional system for the collection, analysis, dissemination and harmonization of data on persons with disabilities.
6. To strengthen collaboration between disabled people’s organizations (DPOs) and bureau of statistics to ensure that data and statistics is accessible to policy makers, persons with disabilities and others.

3.2.2 Expected outcomes of the workshop

In view of the objectives, the workshop had the following expected outcomes:

1. Strengthened capacity for disability measurement and use of disability statistics and research in Member Countries of and the SADC region.
2. Increased understanding of disability statistics and research for equal employment opportunities for persons with disabilities.
3. Collection of ideas and methodologies for national improvement in identifying disability
4. Information on excellence in data accuracy and dissemination that include disability shared through professional networking

5. Partnership/collaboration between bureaus of statistics and DPOs strengthened

4. **Day One**

4.1. **Key Points and Conclusions, Day One**

Day One of the workshop was targeted at providing the participants an in-depth understanding of the state of statistics as well as the state of statistics in relation to the living conditions of persons with disabilities, and their role and place in national wellbeing, employment creation and poverty in the SADC region. While countries like Zimbabwe and Zambia had just completed national disability surveys before the meeting, participants learned and acknowledged that other countries in the region were working towards adopting enumeration instruments that would accurately capture persons with disabilities. Bureaus of Statistics, Departments of Labour and Social Development, Disability Federations from eight of the 15 member states of SADC and international organizations were represented at the meeting as listed below:

1. Botswana
2. Lesotho
3. Madagascar
4. Malawi
5. Namibia
6. South Africa
7. Zambia
8. Zimbabwe
9. Christoffel Blindenmission (CBM)
10. the European Union (EU)
11. the International Labour Organization (ILO)
12. the United Nations Children’s Fund (UNICEF)
13. the United Nations Development Programme (UNDP)
4.2. The State of Disability Statistics in the SADC region

The key to developing an action that will strengthen, promote and protect the rights of persons with disabilities and meet their needs in the SADC region is to first understand the state of information regarding the persons with disabilities in the region from research and disability organizations in SADC member states.

In addition to the highlighted challenges (Section 2.1.2) facing persons with disabilities in the SADC region, most governments in the region are only now beginning to officially recognize persons with disabilities and the role of such persons in local economic policies, which are currently not conducive to the wellbeing of these persons in most countries. This is largely due to the negative perception, stigma and stereotypes around persons with disabilities who are viewed as a burden.

The workshop started with welcome remarks to participants by the Deputy Director of the Centre for the Study of Governance Innovation (GovInn) at the University of Pretoria, Dr. Chris Nshimbi. The welcoming remarks were followed by statements by the Africa Disability Alliance Chief Executive Officer, Mr. A. K. Dube, Ms. Judith Van de Veen of Christoffel Blindenmission (CBM), Mr. Arno Schaefer, Minister Counsellor, Head of Cooperation, Delegation of the European Union to the Republic of South Africa, Dr. Coffi Agossou, ILO Statistics Expert and a keynote address by GovInn Director, Professor Lorenzo Fioramonti.

4.2.1 Opening Statements

1. Mr. A. K. Dube, CEO, Africa Disability Alliance

In his statement Mr. Kudakwashe Dube introduced the Africa Disability Alliance (ADA) by sharing its vision, mission and strategic focus for the next five years. He further introduced the Communities of Practice in Disability Advocacy for Mainstreaming (COPDAM) project, a continental disability policy.
implementation strategy project aimed at building the capacity of national and regional disability federations to negotiate and advocate for disability mainstreaming in all sectors of government and at the level of the African Union. The project is implemented at both continental and Southern Africa regional levels with focus on Lesotho, Madagascar, Malawi, South Africa, Zambia and Zimbabwe. It is funded by the EU Commission and Christoffel Blindenmission (CBM).

After presenting and elaborating on the objectives of the meeting (see 3.2.1), Mr. Dube concluded his presentation by informing the meeting of the following opportunities that had emanated from ADA’s collaboration with the AU, regional economic communities, African Governments and other stakeholders:

a) The political good will by government and the empowerment of DPOs have opened up opportunities that need to be sustained and supported,

b) Demand for capacity building of government officials to be able to budget and monitor the implementation of the NDMP,

c) The need to track the implementation of the NDMP by strengthening the participation of DPOs,

d) Documentation, publishing and sharing of best practice in disability mainstreaming, and

e) Generation of disability disaggregated data to inform plans and service provision.

2. Ms. Judith Van de Veen, Christoffel Blindenmission (CBM)

Ms. Van de Veen introduced CBM and its work. CBM works globally with more than 650 partners who are active in over 70 countries. CBM’s vision is to have an inclusive world in which all people with disabilities enjoy their human rights and achieve their full potential. CBM is committed to improving the quality of life of people with disabilities around the world.

CBM is a proud partner of ADA and enjoys the collaboration. CBM also appreciates the way in which the COPDAM project has facilitated the drive of the continental disability agenda by continental DPOs, the relationship with the African Union, governments and universities.

Ms. Van de Veen also acknowledged the way in which the SADC governments had embraced the
development of national disability mainstreaming action plans and looked forward to seeing cross sectorial commitments to the implementation of inclusion of disability. This will call for ensuring monitoring systems are in place. The availability of data will help governments to establish targets, indicators and how goals are being reached. She hoped the workshop on disability statistics would help make disability more visible.

3. Dr. C. Agossou, International Labour Organisation

Dr. Agossou spoke on behalf of the Director of the ILO/Decent Work Team for Southern and Eastern Africa, Mr. Vic Van Vuuren, who sent apologies for his absence from the workshop. He went on to point out that since 1999 the promotion of decent work, defined as “productive work in conditions of freedom, equity, security and human dignity”, has become the main objective of the ILO. The 2008 ILO Declaration on Social Justice and a Fair Globalization reaffirmed the commitment of Member States to promote decent work based on the four equally important strategic objectives, namely promoting employment, developing and enhancing measures of social protection, promoting social dialogue and tripartism, and respecting, promoting and realizing the fundamental principles and rights at work.

Further, he pointed out that the promotion of labour market information systems had been identified as one of the priority areas in the achievement of decent work outcomes in Africa. A number of countries on the continent have prioritized Labour Market Information within their Decent Work country programme. Strengthening the data collection for labour statistics including disability statistics was identified as a priority in a number of key meetings and forums on Africa such as:

- the Extraordinary Summit of the African Union on Employment and Poverty Alleviation in Africa (Ouagadougou, Burkina Faso, September 8-9, 2004),
- the 39th session of the Conference of African Ministers of Finance, Planning and Economic Development (Ouagadougou, May 2006),
- the 11th ILO African Regional Meeting (Addis Ababa, April 2007),
- the 97th Session of the International Labour Conference (Geneva, June 2008), which called for “the establishment of appropriate indicators or statistics, if necessary with the assistance of the ILO, to monitor and evaluate the progress made”,
• Malabo Declaration on Youth Employment (2011), that calls for the reduction of youth employment by 2% per year;
• The Conference of African Ministers of Finance, Planning and Economic Development held in Addis Ababa in 2012 who calls Member States for data production annually.

Dr. Agossou informed the workshop that the need for the creation of a SADC Labour Market Information System (LMIS) was approved by the Integrated Committee of Ministers (ICM) in June 2007 and reiterated by the SADC Ministers responsible for Employment and Labour and Social Partners in Maseru in April 2008. The LMIS is one of the key priorities in the SADC Decent Work Programme approved in May 2013.

He also told the workshop that in terms of Data collection, in most African countries there is
• No data series, no regular Labour Force Survey: not even at every 5 years,
• No systematic use of international standards/ concepts,
• Lack of harmonized/ comparable indicators,
• Different coverage (national or urban only),
• Different thresholds: hours of work, minimum wage, etc.
• Some concepts not well/ clearly defined at national level: e.g. informal employment, child labour.

Moreover, in December 2013, within the framework of the implementation of the Decent Work Programme 2013-2019, with ILO support, a consultative meeting was held for SADC Member States in Johannesburg, South Africa. Participants of this workshop proposed a harmonized labour market information tool to be related to the employment report, labour migration and disability module. The SADC Ministers and Social Partners at this meeting approved 3 tools, namely:
• the draft template for employment report,
• the module on labour migration, and
• the module on disability that is composed of 3 questions to be integrated in the LFS questionnaire (see Appendix).

In this regard, the ILO assisted the Zimbabwe National Statistics Agency (ZIMSTAT) to include this questionnaire in the 2014 Labour Force Survey (LFS). A report based on this exercise has since been released.
Dr. Agossou put the number of people with disabilities at an estimated one billion, or 15 per cent, of the world’s population. About 80 per cent are of working age. The right of people with disabilities to decent work, however, is frequently denied. People with disabilities, particularly women with disabilities, face enormous attitudinal, physical and informational barriers to equal opportunities in the world of work. Compared to non-disabled persons, people with disabilities experience higher rates of unemployment and economic inactivity and are at greater risk of insufficient social protection that is a key to reducing extreme poverty.

The ILO has a longstanding commitment to promoting social justice and achieving decent work for people with disabilities. It takes a twin-track approach to disability inclusion. One track allows for disability-specific programmes or initiatives aimed at overcoming particular disadvantages or barriers, while the other track seeks to ensure the inclusion of disabled persons in mainstream services and activities, such as skills training, employment promotion, social protection schemes and poverty reduction strategies. ILO efforts to include people with disabilities also cover the full spectrum of its activities, including its internal practices and partnerships with other UN agencies, as outlined in the ILO Disability Inclusion Strategy and Action Plan 2014-17. The ILO Disability Programme promotes decent work for women and men with disabilities and facilitates means to overcome the obstacles preventing people with disabilities from full participation in the labour markets.

Dr. Agossou informed the workshop that his ILO colleague based in Geneva, Mr. Stefan Trömel, would speak to the workshop on Day Two on, among other things:

- Some general Information on employment of persons with disabilities
- The UN Convention on the Rights of Persons with Disabilities
- Challenges related to employment statistics of persons with disabilities
- The need to disaggregate employment statistics by disability as a requirement originating from the negotiations of the Sustainable Development Goals
- The Washington Group module on persons with disabilities
- Other global initiatives in the area of disability measurement
- An advance on the work currently being done to develop a module on persons with disabilities to be included in Labour Force Surveys.

Dr. Agossou reiterated that the workshop was a milestone that would contribute towards the development of the SADC Labour Market Information System. Availability of reliable,
comprehensive and up-to-date Labour Market Information is a necessary condition for effective manpower planning and implementation that include decent work for people living with disabilities. Governments, investors as well as for individuals and educational institutions, require such information.

4. Mr. A. Schaefer, Delegation of the EU to the Republic of South Africa

His Excellency, Mr. Schaefer pointed out that the EU, the AU, and SADC had the same obligations towards the disabilities component on training for special needs teachers. The EU has adopted the European Disability Strategy 2010-2013. The European Union also supports academic networks among European disability networks. Mr. Schaefer indicated that a lot of work remains in the area of disability and statistics.

5. Professor L. Fioramonti, Centre for the Study of Governance Innovation, University of Pretoria

In his keynote address to the workshop, Professor Fioramonti noted that the struggle for people with disabilities to see their aspirations, needs and capacities reflected in national statistics is part of a larger struggle to have statistics reflect a different type of economy, which should aim to achieve human development and wellbeing rather than mere growth in output. It is precisely through the conventional lens of mainstream economic statistics that the role of people with disabilities is seen as marginal or irrelevant, when not described as a burden for society. By contrast, a statistical system designed to help our societies increase human development and wellbeing would recognize not only the important role of people with disabilities in strengthening social cohesion and performing activities that are often marginalized by conventional economics, but it would also show how a society based on community development and social capital enormously increases the capacity of people with disabilities to live a happy and fulfilling life. Our current economic system, and the statistics based thereon, are 'blind' to the multifaceted inputs that people with disabilities can provide to societal wellbeing. The struggle of people with disabilities must be seen as part of radical drive towards changing the statistics that are used to design policy with a view to
changing the economy.

6. Ms. Mary Liaga, former Teacher, St. Francis Catholic School, Limpopo, South Africa

Speaking from her experience in teaching mathematics and physics to Grade 11 and Grade 12 learners with visual impairments or blind at St. Francis Catholic School in Limpopo Province, South Africa, Ms. Liaga highlighted a number of challenges faced by both teachers and learners which can be addressed if decision makers were provided with accurate disability statistics and the status of persons with disabilities.

- Textbooks
- Teachers
- Equipment
- Exclusion of learners
- Funding to include all learners with disabilities through the provision of modern learning aids such as electronic gadgets and devices

4.3. Country Reports and Presentations

Each SADC country present at the workshop gave brief presentations giving an overview of their work regarding statistics and disability.

Following are the statistics and disability experiences and lessons for the countries (in order of presentation):

4.3.1 South Africa

South Africa has seen the advancement of rights of persons with disabilities and is addressing development related challenges. Through its National Development Plan (NDP), government outlined the roadmap towards disability strategies and interventions aimed at improving the lives of persons with disabilities. However, barriers relating to the environmental and access, legal, institutional, as well as attitudinal barriers still exist and often translate into social exclusion and vulnerability of this group.
In terms of measurement, disability has traditionally been viewed from a medical and welfare perspective. Based on this approach, persons with disabilities were grossly underestimated, their social needs neglected and human rights violated for decades. However, the latest round of censuses (2010 Round of Censuses) used the psycho-biological social model of disability, advocated for by the UN Convention on the Rights of Persons with Disabilities, and the International Classification of Functioning.

In view of the measurement advocated by the Washington Group on Disability Statistics, implementation of this tool in Statistics South Africa (Stats SA) Surveys came through a comprehensive research study conducted in 2005/06 at Stats SA on replacement of the previous disability module with the proposed module from the Washington Group (WG). The findings from the study showed that the proposed WG module could be used effectively in replacing previous modules in surveys conducted by Stats SA to measure disability.

Analysis of General Household Survey (GHS) data on disability based on the Washington Group type of questions has shown that the percentage of persons classified with disabilities remained relatively consistent, if the standard classification namely, “persons who were unable to” or “experienced a lot of difficulty doing any one of the activities mentioned” or “Some difficulty” for two or more of the six dimensions was used. Coverage from GHS was consistent: prevalence at 5.4% in 2012, 5.8% in 2013. Census 2011 used a similar approach of profiling disability status. Importantly, it was immediately realized that the answers for children aged 0-4 were very variable and that disability prevalence were very high for these ages.

Other gaps and limitations that Stats SA still faces include misreporting and other potential biases, coverage by census and surveys, measurement of child disability, measurement of disability in institutions, measurement of particular types of disability, e.g. psycho-social disabilities, different definitions for disabilities used for the question and by various government departments.

The way forward for Stats SA regarding disability statistics includes testing of the new childhood disability module. Stats SA together with the Department of Social Development (DSD) and the UNDP is currently planning a research study to test this new childhood disability module in South Africa. Further, disability will continue to be measured annually in the GHS and the national census every ten years. Stats SA together with relevant stakeholders will continue advocating for a specialized survey to measure disability. Also, Stats SA will assess the feasibility of using administrative sources of data to collect and report information on disability, particularly in
institutions.

4.3.2 Zambia

In Zambia, various routine and non-routine methods of data collection are used. Routine data is collected through Disable People's Organisations (DPOs) and coordinated by the Ministry in charge of disability. However, the participants from Zambia reported that the routine method is limited and does collect a lot of information. On the other hand, non-routine data are collected through censuses and surveys. This method too was reportedly not able to collect a lot of information, as it only has a few questions on disability.

The gap in data collection was noticed while efforts were being made to make improvements. Further, Zambia had just completed the National Disability Survey exercise. This survey tried to be all-inclusive during the consultation phase while at the same time engaging all organizations and stakeholders.

4.3.3 Malawi

In Malawi, specific surveys or researches are initiated and/or managed by respective institutions or individuals for various purposes such as informing policies, programmes or projects and academic. For instance, in 1983 the National Statistics Office conducted a national sample survey on disability that showed that 3 per cent of the population had disabilities while the 2008 Population Census presented questions on disability and the data analyzed reported that 3.8 per cent of the population had various kinds disabilities. A number of specialized studies have also been conducted in Malawi including the 2011 Situation Analysis of Persons with Disabilities in Malawi and the 2012 Children with disabilities study.

Malawi has strengthened its efforts to promote participation (capacity building) of persons with disabilities in undertaking research and dissemination through national and regional or international networking. Persons with disabilities were also involved as enumerators and supervisors in the 2003 survey. The survey used the International Classification of Functioning (ICF) model in defining disability in terms of activity limitation and participation restriction.

Some of the challenges relating to disability statistics presented by Malawian participants included:
• Definition of disability with respect to national surveys and censuses resulting in low national prevalence rate for disability
• Lack of comprehensive baseline or benchmark data to assist in determining progress
• Lack of comprehensive data on children with disabilities;
• Lack of disability mainstreaming among research institutions and
• Lack of financial resources.

4.3.4 Zimbabwe

The Zimbabwe National Statistics Agency (ZIMSTAT) is a semi-autonomous body established through an Act of Parliament in 2011 to oversee all data collection activities in the country. The Agency is responsible for conducting all large-scale data collection activities such as the Population Census and Demographic and Health Surveys.

Zimbabwe uses census, population surveys and administrative data registries to measure disability. The purpose of statistics on persons with disabilities and their circumstances is to improve efforts at removing disabling barriers and providing services to enhance the participation of such persons in society and identify strategies to improve their wellbeing in Zimbabwe. However, the cited measures of data differ according to purpose and application of the data.

Disability in Zimbabwe is estimated at 7.0 per cent, accounting for about 900,000 people. The most prevalent disabilities according to the Level of Living Conditions Survey 2013 include difficulty seeing (13.9 per cent), walking (12.6 per cent), hearing (6.8 per cent) and remembering (6.6 per cent).

Challenges faced include:

• Morbidity and mortality rates are higher in households of persons with disabilities
• Fewer persons with disabilities access formal education
• A large proportion of individuals with disabilities are children
• Natural environment is perceived as the most common environmental barrier and
• Harmonizing resource mobilization efforts with other partners to collect more disability statistics

According to the Zimbabwean participants, strengthening resource mobilization efforts for surveys that provide more detailed data on dimensions of disability based on ICF concept would enable
capturing of information on contextual components associated with disability-participation and environmental factors. This would require high coordination and the involvement of stakeholders in planning, implementation and utilization of data.

4.3.5 Namibia

Namibia has adopted the UN Convention on the Rights of Persons with Disabilities but is still struggling with the definition of disability. However, disability groups in the country work closely with data collection agencies. The disability database aimed at registering all persons with disabilities in Namibia will be housed in the Office of the Prime Minister.

4.3.6 Madagascar

The participants from Madagascar reported that the country has constant data collection, which is also available in different sectors. For instance, the health sector has the Health Statistic System at the National Level, which involves filling a monthly and yearly activities report on public and private training on activities related to cure, prevention, maternity & inputs management. However, disability data are only reported by specialized institutions. In the education sector, a monthly data report from the public and private primary and secondary schools exists but does not consider data on persons with disability. Even regarding civil status, the regular filing and registration of the civil status including birth, death, marriage, divorce, adoption, etc. does not consider disability data. Such data in statistical publications are practically nonexistent with the only exception being some urban centers. Moreover, persons with disabilities are not represented in the Ethical National Committee, which validates the household questionnaires.

The participants from Madagascar concluded that data on persons with disability are not taken into consideration in the reporting system in the country’s different sectors including health, education, employment and civil status. Therefore, the participants identified as crucial the need for collaboration with other development stakeholders including the Inter-ministerial committee, Institut National de la Statistique (INSTAT), Ministère de la Population et des Affaires Sociales (MINPOP), La Plateforme des Fédérations des Handicapés de Madagascar (PFPH), CBM, Handicap International, the UN, Washington Group and ADA and other international organizations that have experience in the area of disability data collection.
4.3.7 Lesotho

The monitoring system used to collect data on persons with disabilities followed the Disability Module that was used since the country’s 2001 Demographic Survey up to the 2011 survey. This included a list of questions on type of disability, causes of disability, and duration of disability. Currently, the Disability Module to be used in Lesotho’s 2016 Population and Housing Census includes the following questions.

**Does (name) have difficulty in the following:**

- Seeing, even when wearing glasses for those who usually wear them?
- Hearing, even when using hearing aid (for those who usually use them)?
- Communicating in his/her language (i.e. understanding others or being understood by others)?
- Walking or climbing stairs?
- Remembering or concentrating?
- With self-care such as washing all over, dressing or feeding?

**Responses**

- No difficulty
- Some difficulty
- A lot of difficulty
- Cannot do at all
- Cannot yet be determined
- Don’t know

Apart from difficulties in collection, the data collected on persons with disability in Lesotho in the past two decades has also been insufficient. According to the participants from Lesotho, the challenges that the country faced in the collection of data of persons with disabilities include:

- Implementation. Moreover, while multiple agencies are involved in disability issues, no effective mechanisms for disability exist.
- Insufficient expertise on disability issues e.g., occupational therapists
- Lack of reporting by sectors for persons with disabilities
- Lack of targeted livelihood programmes for the vulnerable. Existing programmes are not
inclusion of persons with disabilities (PWDs)

- Lack of funding for the integrated education of persons with disabilities
- Lack of comprehensive data on other socioeconomic variables and other administrative records.

- The participants from Lesotho, therefore, gave the following recommendations:

  - Increase access of persons with disabilities to services through supermarket approach: diminish silos of individual organizations in disability
  - Increase capacity for officers in charge of disability by requiring reports on persons with disability services
  - Increase reporting on community-based rehabilitation (CBR)
  - Increase reporting on human rights violations of persons with disability
  - Increase reporting by government agencies on services to persons with disabilities in all areas—health, education, social protection, and justice.
  - Construct disability database of services for persons with disability for improved access by the persons with disability and better management by stakeholders.

4.3.8 Botswana

Botswana collects disability data through surveys and the national census, conducted by Statistics Botswana in collaboration with other ministries. A Coordinating Office for People with Disabilities in the Office of the President was established in 2010 with a mandate to develop and coordinate the implementation of policies, programmes and strategies aimed at empowering people with disabilities.

The 2006 Botswana Demographic Survey revealed that disability is more prevalent in rural areas than in urban areas. This was consistent with previous censuses. Defect of vision in both eyes was the most common type of disabilities reported (41.1 per cent of all people with disabilities).

The Challenges faced in Botswana included:

- Over reporting, in cases where some people may have more than one disability (multiple disabilities). An individual with more than one disability may, therefore, be counted in each category of disability.
- Under reporting due to the fact that different people understand disability differently. What one respondent may consider a disability may not be seen as such by another
respondent. Therefore, there may be underreporting as some respondents may report only what they consider to be a major disability.

- Another source of underreporting is the fact that there is stigma attached to disability.

These factors may result in respondents not being able to freely reveal the disability status of members of their households. However, the participants from Botswana reported that efforts are in place through the National Coordinating Office for People with Disabilities to coordinate all departments on disability issues by, for instance, increasing training, public awareness and sensitization through the media, workshops and other activities and strategies aimed at changing society’s attitudes towards people with disabilities.

4.3.9 UNICEF

Mr. Shikwe, the workshop participant from UNICEF shared a new survey module on child functioning and disability that UNICEF has been developing in partnership with the Washington Group on Disability Statistics, as part of efforts to address the need for comparable and reliable data on children with disabilities.

The module, which covers children between the ages of 12 and 17, is meant for use in surveys and censuses and is intended to produce internationally comparable data. This module assesses activity limitations in the domains of speech and language, hearing, vision, learning, mobility and motor skills, and emotions.

Its purpose is to identify the sub-population of children and youth (aged 2-17 years) with functional difficulties. These difficulties may place children at risk of experiencing limited participation in a non-accommodating environment. The aims of the module include:

- To provide cross-nationally comparable data
- To be used as part of national population surveys or in addition to specific surveys (e.g., health, education, etc.)
**Development of module**

UNICEF’s first draft of this module was presented at the 11th Washington Group meeting in November 2011, in Bermuda. Revisions to the module were made in April 2012 in Rome followed by the Consultation on the Measurement of Child Disability technical meeting in June 2012 hosted by UNICEF. Then followed the presentation of a new module in October 2012 and the validation process from September 2012 to 2015.

The Module discusses conceptual and theoretical issues related to measuring disability. It includes considerations for designing, planning and implementing the collection of data on children with disabilities.

The questions in the module ask about difficulties the child may have in doing certain activities.

Unless noted otherwise, all response categories are:

- No difficulty
- Some difficulty
- A lot of difficulty
- Cannot do at all

The module is designed to:

- Avoid a medical approach,
- Use the ICF bio-psychosocial model
- Use, when appropriate, questions already tested and adopted by the Washington group
- Include the reference “Compared with children of the same age…”
- Consider age specificity
- Response options reflected disability continuum
- Provide guidance for those considering collecting, analysing and using data on children with disabilities

The module is expected to be ready in early 2016
In efforts to create a society for all, UNDP presented a catalytic approach to enable the scaling up of interventions for immediate improvements in the life of persons with disabilities. Disability is a social phenomenon of enormous complexity. The UN Partnership to Promote the Rights of Persons with Disabilities (UNPRPD) aims to link different specializations into a common platform. The objective is to develop the capacities of national stakeholders, particularly governments and organizations of persons with disabilities, for the effective implementation of the UNCRPD by promoting disability-inclusive internationally agreed development goals. This will be done by:

- Enabling legislation and policy frameworks
- Empowering cultural norms
- Capable and inclusive institutions
- Access to services (mainstream and targeted)
- Access to justice
- Application of accessibility standards to products, environments and processes
- Access to rehabilitation, habilitation including assistive technology
- Adequate data and evidence

4.4. Putting it all together

At the end of Day One, and consistent with workshop objectives and expected outcomes, participants had shared country experiences as well as ideas and methodologies for improvement in identifying disability indicators at national level to enhance measurement from the various experiences and data collection activities. They also shared information on best practices and improving data accuracy and dissemination. Participants also established and strengthened networks, partnerships and collaboration with one another.
5.1. Key Points and Conclusions, Day Two

Day Two of the workshop explored the ways in which disability statistics can be enhanced to contribute to achieving equal employment opportunities for persons with disabilities and was facilitated by ILO.

The day started with a recap of Day One activities and deliberations by Ms. Judith Van der Veen who pointed out the two ways in which disability can be looked at when collecting disability data. She highlighted the social model in which people are considered disabled because of the environment and not the way they are and the structural measurement in which data collectors can ensure inclusion of disability through the health sector, education sector, etc., with emphasis on needs such as text books and braille. Regarding the individual model, limited data on disability will be obtained through surveys, censuses, etc. because such questions as “how many people are disabled?” are asked. Such questions usually lead to results suggesting that the prevalence rate of disability in a population is 3 per cent. However, rephrasing the questions to “do you have difficulty seeing?” or “are there people with difficulty seeing” will yield greater numbers of persons with disability. Ms. Van der Veen informed the workshop that the Washington Group had changed the old way of asking questions designed to obtain information on disability by rephrasing to “do you have difficulty” type of questions. The move towards the Washington Group type of questions is to better capture how individuals function. Moreover, the Washington Group questions are short and give a fairer assessment of people with functional limitations.

Following the recap of Day One, Dr. Coffi Agossou from ILO introduced Mr. Stefan Trömel, Senior Disability Expert with ILO, who spoke via video link from Geneva. Stefan indicated that the workshop was timely, as it coincided with ILO’s current work on disability statistics in Geneva.

5.1.1 Presentation

Mr. Stefan Trömel, Senior Disability Expert, ILO

After introducing himself, Stefan highlighted some general information on employment of persons with disabilities indicating the higher levels of unemployment among such persons; that some are not even seeking employment; the lower salaries they get; and that there exists an overrepresentation of persons with disabilities in the informal economy. Further, information, if it
exists, does not tell anything about the barriers or availability of support for persons with disabilities

Stefan also highlighted initiatives in lower income countries to revive social protection and the accompanying need to improve statistics in employment and social protection. Disability inclusive social protection is recommended despite the nonexistence of social protection statistics and information on the extra costs of disability (South Africa is a good example in this).

Stefan indicated that the UN Convention on the Rights of Persons with Disabilities, to which all countries in Southern Africa are State Parties, is a milestone and amazing step forward for persons with disabilities especially as reflected in Article 27 and Article 28. Article 31 requires availability of statistics.

Regarding challenges related to employment statistics of persons with disabilities, Stefan asked why it has been complex to get statistics on disability and why huge differences exist in the percentage of people with disabilities between countries. The answer lay in the fact that different countries use different definitions. Some countries have narrow definitions, which only ask, for example, if people are blind, deaf or use wheelchairs. Other groups of disabilities such as the mental are not included in national definitions. The UN Convention does create a global definition but establishes a threshold.

However, the difference in definition is not essentially the problem. In looking at access to benefits it is important for governments to establish thresholds from a policy point of view. It is more complex from a statistics point of view. The problem lies with measuring disability: how do we ask the question? What question do we include to determine the prevalence of disability? The question “Do you have a disability?” elicits different kinds of answer because of, among other things, stigma and difficulties in translating into other languages.

Stefan explained that attempts to overcome this triggered the work of the Washington Group. The Washington Group produced a short set of six disability questions (activity limitation) with 4 response categories. The objective of the 6 questions in this module is to determine disability without using the word, “disability.” Rather, the questions are framed in the form “Do you have difficulty walking?” etc. Evidence shows that the movement from traditional questions to Washington Group questions moves the statistic of persons with disabilities from 3 per cent to 12 per cent.

According to Stefan, in the past the excuse for not providing disaggregated disability data was
because it was difficult to measure. Now a tool exists. The need to disaggregate employment statistics by disability is a requirement originating from the negotiations of the Sustainable Development Goals (SDGs). The whole SDG document makes reference to persons with disabilities. A specific example includes the reference to persons with disabilities in Goal 8 on Decent Work. According to Stefan, these are good developments (also the latest meeting in Addis on Financing for development makes reference to persons with disabilities in the formal labour market). The WG is the response to the concern that information cannot be disaggregated by disability.

Stefan also highlighted other global initiatives in the area of disability measurement including UNICEF on child functioning (to replace the WG module which does not work for children), the School module developed between UNICEF and WG, and the World Health Organisation (WHO) Model Disability Survey.

The WHO Model Disability Survey provides a template for national surveys. It can provide much more information; is applied to a representative sample of households; allows comparison between disabled and not disabled and also between severely disabled and moderate disability; assesses the impact of barriers and available support; seeks to ensure comparability and is in line with the UN Convention.

Further, Stefan highlighted:

- The advance on the work currently being done to develop a module on persons with disabilities to be included in Labour Force Surveys, a joint initiative with the ILO Statistics Department (standard setter of labour force surveys)
- Updated compendium of national methodologies on employment statistics of persons with disabilities (just released)
- Recent expert meeting as part of a UN funded project with other UN agencies, some NSOs and DPOs
- Longer module that seeks to identify additional issues beyond showing that there is a problem. This will include:
  - Onset of disability
  - Availability of reasonable adjustments
- Attitudinal barriers
- Disability benefits

This is to be inserted every 2-3/5 years in a Labour Force Survey and is currently in the process of cognitive testing

- The relevance of building capacity of all stakeholders, in particular also of DPOs

### 5.1.2 Questions and Answers based on Stefan’s presentation

1. **Q.** How important is it for statistics departments in our countries to consider including persons with disabilities in their work?

   **A.** The overall message from the UN Convention is that persons with disabilities need to be involved in all stages of implementation of the convention, which also includes statistics. It is important for disability organizations to be involved in processes, as they have the right to do so. It is important for statistics offices to understand disability but also for disability organizations to understand statistics.

2. **Q.** Is it not possible to have one definition to include all persons with disabilities regardless of country?

   **A.** UN Convention Article 1 does not produce a final definition but says that disability arises from interaction of a person who has impairment with an environment that is not conducive. The social model is clear. Also, disability is an evolving concept. New things have appeared: mental, due to stress at work; car accidents; people living with HIV, etc. The concept of disability has been changing. It is risky to try and come up with a definition because it will not stand the taste of time. Also, you might want to use different definitions even within the same country for purposes of specific programmes, e.g. for giving out disability grants as the case in South Africa where disability may be defined for purposes of enabling applicants access grants. It is, therefore, impossible and probably not desirable to have a uniform definition.

3. **Q.** How can the information in the six questions be disseminated to labour ministries and how can we get the new Washington Group questions to be included in labour surveys?
A. There is need to convince and put pressure on statistical offices that work with ILO. However, such pressure must be accompanied with good guidance through analysis of the information obtained from these instruments. Effort should be made to adequately extract information from the additional information obtained through these instruments and analyse it for policy makers.

4. **Q.** What is the difference between the ICF and ILO?

A. The link between the ICF and ILO: ILO is working closely with the World Health Organization (WHO), which requested ILO to improve the employment section in the disability survey. The Washington Group, UNICEF, World Disability Survey, all are inspired by the UN Convention and trying to go beyond just identifying the number of people with disabilities in order to identify lack of participation, links to the environment, etc. This is more consistent with the social model.

5. **Q.** Does the addition of the six questions to existing census or surveys mean more time spent in administering the questionnaires and does it add to the cost of running a survey?

A. The difference between asking the old questions and the newer ones is that the newer questions generate more information. There is a cost element in including the newer questions.

There is need to convince or pressure statistics offices to use the six questions in surveys. However, it is important to accompany the pressure with good guidance through analysis of that information. Effort should be made to adequately extract information from the additional information obtained through these questions and analyze it for policy makers.

5.2. **Country Presentations and Feedback from Break-away Discussions**

In the session following Stefan’s presentation, participants broke away into small groups to discuss the following questions:

1. **What information do we need from a policy, programme planning and monitoring point of view?**
2. **Are there any initiatives in your country to obtain this information? Reflect on your
presentation yesterday look at the sectors of health, education, employment and social protection.

3. What more needs to be done to have a better disability related statistics especially in regard to health, education, employment and social protection?

4. Recommendations and priorities for future work on disability statistics in your country.

Each country gave brief feedback presentations based on the discussions held during the breakaway session, as follows:

5.2.1 Zambia

1. Information needed from a policy, programme planning and monitoring point of view

Participants from Zambia deliberated the above question in relation to their own environment and the following was identified as the information needed:

- Policy interventions
- How disability is going to be mainstreamed in different sectors
- An elaborate outline of implementation plan of activities
- Budget associated with outlined implementation plan of activities
- Targeted sectors to be dealt with
- Deal with various stakeholders
- Access to the various issues and facilities associated to people with disabilities e.g. buildings, schools, health facilities, etc.
- A good monitoring system on how things are done

2. Initiatives in Zambia to obtain the information in (1) above

The education sector is making headway by trying to introduce issues to deal with disabilities in the curriculum for instance by trying to put up the construction of building with access.

The health sector, although making progress, should try and collect more data from the HMIS, put
out an implementation plan

In general, the participants agreed that there is need for a proper plan on how to deal with people with disabilities from the few existing schools for the disabled and follow them up and their integration in society. There is also progress in mainstreaming the institutions designed for people with disabilities to include people without disabilities. The headway has been identified also in retail stores like Pick and Pay and Shoprite who are employing people with disabilities.

However, due to change in technology, there has been a huge disadvantage, which leads to government not employing disabled people.

3. Further needs for better disability related statistics, especially in regard to health, education, employment and social protection

It is thus important for the line ministry in charge of disability to engage and try to put up a mandate to make sure all ministries and government institutions together with stakeholders provide disability statistics. This should also be complemented by the empowerment of the statistical agencies that collect statistics on disabilities.

4. Recommendations and priorities for future work on disability statistics in Zambia

The participants concluded by recommending that since Zambia has just done the disability survey, they will have to make sure the data is utilized. That is, all government departments and programs should make sure they incorporate all the necessary statistics collected and ensure that they are used to mainstream disability. This will ensure that all policy decisions are based on the statistics produced.

There was also need to domesticate international recommendations and decisions for comparability and the finalization of the M.E framework for the implementation plan

5.2.2 South Africa

1. Information needed from a policy, programme planning and monitoring point of view

Policy Framework
• Employment Equity Act
• White paper on rights of the people with disability
• Integrated National Disability Strategy (INDS)
• National Development Plan (NDP)
• White Paper for Post School Education
• UN conversion on the rights of person with disability (UNCRPD)

Programme Planning

• Baseline information for indicators not available
• Data available not relevant to measure and monitoring
• Utilization of available information is not sufficient

Monitoring

• Synergy between information available and programme
• Alignment of planning and strategic priorities
• Efficient dissemination of reports
• “Reporting fatigue” experienced by officials

2. Initiatives in South Africa to obtain the information in (1) above

Health

• Early detection of developmental delays/ disability (NISPIS)
• National Mental Health Policy Framework and Strategic plan
• Office of Health Standards of Compliance (OHSC)

Employment

• Employment Equity Act
• Reasonable Accommodation Policy
• Technical assistance guidelines
• Personnel and Salary System (PERSAL) System
• The Public Service Job Access Implementation Guidelines and Plan on the Recruitment, Employment and Retention of Persons with Disabilities
• Two percent National target on Employment

Education

• Basic Education
  • Early Childhood Development Policy
  • White Paper 6 on inclusive education

• Higher Education
  • South African Higher Education Open Data (HEMIS)
  • National Skills Development Strategy (NSDS)

Social Protection

• Early Childhood Development
• Social Assistance (i.e. grants)
• Funding for NPO

3. Further needs for better disability related statistics, especially in regard to health, education, employment and social protection

• Governance and Coordination of Disability Agenda to be in the Presidency.
• Policy Mainstreaming
• Psycho-Social disorders need to be also prioritized
• Data Collection System talk to each other
• Economic Active Population (EAP) for person with disability
• Employment Service of SA (ESSA)
• Teacher training on disability
• Integrated Schooling System

4. Recommendations and priorities for future work on disability statistics in South Africa
• Web Portal on work done by all government departments and other stakeholders on disability
• Disability Costing Model
• Disability Inequality Index
• Economic Empowerment Fund

5.2.3 Malawi

1. Information needed from a policy, programme planning and monitoring point of view

The participants representing Malawi required

• Actual numbers of persons with disability disaggregated by type of disability, gender, age, education, employment and location
• Information on access to services like health and rehabilitation, education and training facilities and opportunities, employment, social support services by type of disability
• Extent to which other national policies and national development plans have mainstreamed disability
• Programme planning and monitoring
• Information on participation of persons with disabilities in socioeconomic activities including planning, evaluation and monitoring
• Information on the existing programmes and services that are targeting persons with disabilities including players and stakeholders’ coverage

2. Initiatives in Malawi to obtain the information in (1) above

The participants agreed that there has been improvement for better reporting on disability. These improvements included:

• The inclusion of questions on disability in population census and producing a thematic report on disability
• Disability Management Information System managed by Malawi Council for Handicapped (MACOHA) for the CBR programme
• Developing an integrated Disability Management Information System (comprehensive) led by line Ministry on Disability and NSO
• Disability mainstreaming project where a mainstreaming strategy is being developed with an M&E framework
• Each sector – ministry, departments and parastatal (Health, Education, Youth, Finance, Agriculture, etc.) have focal persons on disability that reports to the line ministry of disability on progress of mainstreaming. Reports also come from district councils and disability Directory

3. Further needs for better disability related statistics, especially in regard to health, education, employment and social protection

The participants suggested four areas that need to be improved and looked at for better disability related statistics, namely;

• Other national surveys to collect data on disability
• Other information systems to capture data on disability
• Build capacity of DPOs to undertake research in various areas
• Need a stand-alone survey on disability

4. Recommendations and priorities for future work on disability statistics in Malawi

The participants made the following recommendations:

• There is need for the National Statistical Office, Ministry of Disability and DPOs to establish a technical working group on disability statistics within the Sector Working Group on Social Support
• Conduct a stand-alone survey on disability
• Urgently finalize the National Disability Mainstreaming Strategy- disseminate and implement
• Build capacity of the National Statistical Office on disability statistics
• Ensure that disability is a cross cutting issue in the next Malawi Development Strategy currently being developed
5.2.4 Zimbabwe and Namibia

1. Information needed from a policy, programme planning and monitoring point of view

The presentation from participants from Zimbabwe reviewed the information needed from a policy, programme planning and monitoring point of view:

- Data on PWDs contributing to the economy through the informal sector
- Economic cost of disability
- Skills and Qualifications mix amongst PWDs
- Labour Market Demands
- Accessibility of the work environment—structural, informational, ICT
- Inclusiveness of company workforce profiles across the organisational hierarchy
- Inclusion of provisions for affirmative action/employment quotas
- Conformity of companies to government provisions regarding employment of PWDs
- Legal sanctions against non-conformity by employers
- Household characteristics

2. Initiatives in Zimbabwe and Namibia to obtain the information in (1) above

Different initiatives have been taken to obtain information as stipulated above. They are categorized below.

Education

- Number of Special Schools
- Resource units
- Level of inclusiveness of mainstream schools and tertiary institutions
- Level of support towards learners with disabilities
- Consideration of disability in curriculum design for teachers
Health

- Rehabilitation villages registers
- Village Health Worker Programme registers
- At Risk Sticker Program for monitoring of new born babies at risk of being disabled
- Community Based Rehabilitation System reports
- Number of PWDs accessing quality assistive technologies
- Inclusion of disability rights in training for service providers

Social Protection

- Number of PWDs accessing specialist services
- Case Management System records
- Number of PWDs accessing social security schemes/assistance
- Number of PWDs accessing loans for IGPS

3. Further needs for better disability related statistics, especially in regard to health, education, employment and social protection

There were also a few areas that needed improvements including the need for:

A comprehensive national MIS for all service sectors for persons with disabilities

Training of personnel in disability data collection modules

A mechanism to strengthen funding was found very essential

Harmonizing resource mobilization efforts with other partners to collect more disability statistics versus the Silo approach

4. Recommendations and priorities for future work on disability statistics in Zimbabwe and Namibia

Despite the progress, the following recommendations were made.

- Engagement of stakeholders through training on current disability models and modules for disability data collection
• Ensure existing surveys consider new modules on disability data collection
• Lobby for consideration of country representatives into the Washington Group
• Strengthen stakeholder linkages in planning, implementation and utilization of disability data capturing of information on contextual components associated with disability-participation and environmental factors

5.2.5 Madagascar

1. Information needed from a policy, programme planning and monitoring point of view

The participants from Madagascar identified various areas that needed more information such as on number of age-school children with disabilities, number of people with disabilities in different age groups, percentage of recommendations put in place following the CIDPH, types of disabilities nationally and regionally, causes of disabilities nationally and regionally, proportion of international and national policies, program and projects elaborated with the participation of trained persons with disabilities and putting them in place by taking disability into account as a socio-demographic variable. This will facilitate in the campaign for political inclusion programme.

2. Initiatives in Madagascar to obtain the information in (1) above

Initiatives taken to get that information included the integration of ‘Disability’ as a variable (types and causes) in the general census of 2016

3. Further needs for better disability related statistics, especially in regard to health, education, employment and social protection

The participants identified the following areas that needed improvement

• Improving the disability-related statistics in the health, education, employment and social protection sectors
• Health sector: - including ‘disability’ as a variable in the report forms during the monthly activities
• Education: - including ‘disability’ as a variable in the report forms during the monthly activities
• Employment: - statistics of disabilities in the workplace and statistics of affiliate PWD, specialised institutions, CAM, AKAMA, Orchidées Blanches, etc.

4. Recommendations and priorities for future work on disability statistics in Madagascar

The following recommendations were also suggested.

• Elaborating policy documents for the protection of PWD
• Including the organizations in charge of PWD in the technical committee of the General Census in order to participate in the questionnaire elaboration work
• Including the organizations in charge of PWD in the Ethical Committee to participate in the validation work of the survey questionnaire
• Take actions in order to take disability into consideration during the general routine in the prioritized sector (health, Education, employment, social protection)
• Elaborating action plan to implement those recommendation (building capacities activities, budgets and program)
• Elaborate ‘disability’ as a module while revising the national strategy document of the statistic development (2015 – 2019)

5.2.6 Lesotho and Botswana

1. Information needed from a policy, programme planning and monitoring point of view?

Participants from Lesotho and Botswana emphasized the need for more comprehensive data on disability and related issues including demographics and socioeconomic characteristics of both disabled and non-disabled population. They also suggested a Demographic Health Survey that would cover information on disability as well as Labour Force Survey, Specialized Survey on Disability, which is not yet in place. Also, inclusion of the Child Module and Household Budget Survey would be needed from this point of view. These should be complemented by a system where all the components of disability are incorporated and a good implementation plan, which will improve
disability reporting.

2. Initiatives in Lesotho and Botswana to obtain the information in (1) above

The participants presented different initiatives in the country like the Census, with the Disability Module (Washington Group). However, these initiatives are not comprehensive enough. For instance, in education the only information available is on disabled children that are enrolled in schools and not on the ones that are not enrolled in any schools; the M&E system is also not comprehensive as it hugely isolates the vulnerable Children

3. Further needs for better disability related statistics, especially in regard to health, education, employment and social protection

There is more that needs to be done to have better disability related statistics especially in regard to health, education, employment and social protection, including:

- Advocacy on disability disaggregation data
- Disability modules in the upcoming Labour Force Survey to be held in 2017
- Need to include disability module in the Demographic and Health Survey 2019
- Specialized Survey on Disability (with a module on disability),
- HBS/CMS with a module on disability
- There is need to improve the National Information System. The ongoing assessment for persons with disability should be on a continuous basis and we need to have the database
- Need for severe disability specialized schools

4. Recommendations and priorities for future work on disability statistics

The participants recommended

- Advocacy for data development and the inclusion of a disability-mainstreaming plan in all sectors of the National Strategic Development Plan (that is the indicators in the National Mainstreaming Plan be aligned to the corresponding sectors in the NSDP)
- They also suggested that the M&E System for vulnerable children should have disability disaggregate data, this will be possible largely by,
- Capacity development on key stakeholders (training on disability measurements,
mainstreaming and DPOs to be trained on understanding of statistics)

- Improve coordination amongst key stakeholders

### 5.3. Proposals and Recommendations to the SADC Secretariat

The workshop proposed that the SADC Secretariat:

- Consider drafting a protocol (specifically) on disability and creating a policy framework that addresses disabilities in Southern Africa. Such a protocol will guarantee and provide a platform upon which the region and member states will validate the collection of disability statistics and data.
- Based on this, that the Southern African region establishes an environment in which will be outlined policy measures that will ensure that persons with disabilities enjoy the rights enshrined in the Convention on the Rights of Persons with Disabilities.
- Further, see to it that member states domesticate relevant international and regional disability protocols, legislations and policies and, subsequently, mainstream the interests of persons with disabilities in national programs.

### 5.4. Proposals and Recommendations to the National Governments

National Governments in the SADC region are encouraged to:

- Collect data and include disability-mainstreaming plans in all sectors of their national Strategic Development Plans (NSDP). The indicators in National Mainstreaming Plans should be aligned to corresponding sectors in NSDPs).
- Disaggregate disability data in their monitoring and evaluation (M&E) systems for vulnerable children
- Budget for disabilities
- Develop the capacities of key stakeholders through training on disability measurements, mainstreaming as well as the training of disabled people’s organizations in statistics
- Work on improving coordination among key stakeholders in and associated with the disability sector
5.5. **Proposals and Recommendations to the National Disability Associations/Organizations**

National Disabled People’s Organizations are encouraged to:

- Work on improving coordination amongst themselves and other key stakeholders in and associated with the disability sector
- Develop their capacities especially in disability measurements and statistics
- Build their capacity to undertake research and analysis of disability data to inform policy

5.6. **Proposals and Recommendations to Cooperating Partners and Funding Agencies**

Cooperating Partners and Funding Agencies are encouraged to:

- Furnish disabled people’s organizations and other stakeholders that work with disabled people with information regarding how funds that are made available for disability initiatives, programmes and activities can be accessed.
- Engage the services of disability experts and personnel specialized in disability issues to serve as focal persons on disability in the cooperating partner and funding agencies.
- Increase commitment to issues of disability.

6. **Conclusion and Way Forward**

6.1. **Conclusion**

ADA and GovInn at the University of Pretoria, with financial support from the EU, conceived the idea of a regional workshop on disabilities and statistics with a view to building shared understanding, among government statistics departments in the SADC region and DPOs, of the challenges that persons with disabilities face, and to develop a roadmap of strategies to address these...
challenges through inclusive data collection mechanisms. The workshop not only created an environment for sharing experiences and practices but also provided a platform for the statistical offices and DPOs from the region to discuss broader coordination and collaboration issues, all of which will strengthen collaboration between DPOs and bureau of statistics and provide a basis for the establishment of a regional system for the collection, analysis, dissemination and harmonization of data on persons with disabilities. This should also ensure that data on persons with disabilities is accessible to policy makers, persons with disabilities and other stakeholders.
7.1. SADC Disability Module for Labour Force Survey Questionnaire

SADC DISABILITY MODULE FOR LABOUR FORCE SURVEY QUESTIONNAIRE

OUTCOME OF

CAPACITY BUILDING WORKSHOP ON LABOUR FORCE SURVEY DATA MANAGEMENT IN SADC MEMBER STATES

10th to 11th December 2013

CROWNE PLAZA, Rosebank - Johannesburg, South Africa
Disabilities:

1. Is NAME X limited in any way due to a disability?
   01=Yes
   02=No, (End of this part of interview)

2. What limitations does X have? Difficulty in:
   01= seeing, even if wearing glasses
   02= hearing, even if using a hearing aid
   03= walking or climbing steps
   04= remembering or concentrating
   05= self-care
   06= Communicating
   07= Other: specify

3. What did cause X’s disability
   01= From birth
   02= Accident
   03= Illness
   04= Other