

*CBM- Nossal Institute Partnership for Disability Inclusive Development*

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| **Analytical Piece**  “How can the collection and use of disability data across the Indo-Pacific be strengthened?”  **Prepared By:**  Hasheem Mannan  **Externally reviewed by:**  Mr Seta Macanawai, Pacific Disability Forum  Mr Yanhong Zhang, Population and Social Statistics Section, Statistics Division, UN-ESCAP  **Date:**  30 June 2014  Australian Department of Foreign Affairs and Trade funded the paper within  CBM Funding Order 37893/11.  The contents do not necessarily represent the view of the Australian Government. |

**Purpose**

A recent Lancet Global Health article highlights that seven years after the United Nations Convention on the Rights of Persons with Disabilities (CRPD) was adopted, disability is still largely absent from data collection and monitoring mechanisms in international development[[1]](#endnote-1). This analysis will present the current global situation regarding disability statistics and data collection and identify opportunities to support partner countries to realise Article 31 (Statistics and Data Collection) and Article 32 (International Cooperation).

**Introduction**

Australia, as a nation which has ratified the CRPD, has committed to supporting disability inclusive development (Article 32) and to collecting appropriate information, including statistical and research data, to enable it to formulate and implement policies which give effect to the Convention (Article 31). The eighth goal of the Incheon Strategy for Asia and the Pacific, which was adopted in 2012, is to “Improve the reliability and comparability of disability data”[[2]](#endnote-2). The capacity of governments and other stakeholders to measure changes against international development goals including post-2015 development targets, achievement of implementation of the CRPD, and results of aid investment relies heavily on strengthening data systems to enable effective disability disaggregation.

**Key Messages and Strategic Opportunities**

A summary of strategic opportunities related to how the collection and use of disability data across the Indo-Pacific region can be strengthened is as follows:

* Consider supporting the operationalization of the disability data specific recommendations of the World report on disability and State of the World’s Children.
* Support partner governments to include the Washington Group short set of questions in their next census rounds.
* Support partner governments to include the Washington Group extended set of questions in existing sample surveys such as national household surveys, national health surveys, general social surveys, or labour force surveys.
* Consider supporting country level capacity building workshops on the use of the Washington Group short set, extended set, and the model disability survey.
* Consider resourcing select Central Statistics Offices and Disabled People’s Organisations to participate in the annual meetings of the United Nations Washington Group on Disability Statistics and technical meetings related to the development of the model disability survey.
* Consider provision of technical support to Central Statistics Offices to enable analysis and interpretation of disability data already collected.
* Consider development of advocacy activities to enable National Statistical Systems and Disabled People’s Organisations to seek integration of disability data in regular data collection of national statistical systems.
* Consider resourcing development of standardized measures to ascertain eligibility criteria for disability programs in Low and Middle income countries context.
* Consider provision of technical support to Member States of the United Nations Economic and Social Commission for Asia and the Pacific, to develop and implement capacity building activities which will strengthen data collection in order to benchmark and monitor goals, targets and indicators outlined in the Incheon Strategy.
* Consider ascertaining the current status of the action recommended by the Regional Conference of the Heads of Statistics and Planning in relation to secondary analysis of disability data to learn and support remedying potential data gaps, strengthen technical capacity amongst partner governments and adequately resource stakeholders.
* Consider ascertaining technical challenges and resource constraints faced by the Secretariat of the Pacific Community to include disability as a theme in the Pacific National Minimum Development Indicators.
* Consider ascertaining the current capacity of Australian Non-Governmental Cooperation Program (ANCP) partners to collect and disaggregate disability data and support provision of technical assistance and capacity development to strengthen this.

**Methodology**

The World report on disability and the State of the World’s Children made key recommendations on disability data. Several direct and indirect actions continue to work towards fulfilling these recommendations. This note provides an overview of the current state of disability data and identifies strategic opportunities by critically reviewing the current status of these actions from information available in the public domain. Furthermore, it takes into consideration key disability data initiatives involving United Nations Economic and Social Commission for Asia and the Pacific (UN-ESCAP), and representative Organisations of people with disability such as Pacific Disability Forum.

Direct actions reviewed include the work of the World Health Organisation, United Nations Children’s Fund (UNICEF) and Washington City Group on Disability Statistics. Other actions include the work carried out by:

* UN-ESCAP in relation to the Incheon Strategy
* Secretariat of the Pacific Community in relation to disability data
* United Nations Department of Economic and Social Affairs and United Nations Educational, Scientific and Cultural Organisation in relation to disability data policy recommendations
* ANCP partners.

A final draft of the report was reviewed by key stakeholders from UN-ESCAP and the Pacific Disability Forum.

**Key Issues**

**Washington Group on Disability Statistics[[3]](#endnote-3)**

The mandate for the Washington Group on Disability Statistics grew out of the initial work begun at the United Nations International Seminar on Measurement of Disability in New York on June 4-6, 2001. As a result of the seminar, the United Nations Statistical Commission authorized the development of a City Group focussed on key areas associated with measurement of disability. The National Center for Health Statistics, the official health statistics agency of the United States was invited to host the first meeting, which took place in Washington, DC. The Washington Group has held 13 annual meetings since its inception.

Annual meetings are rotated through major geographic regions to facilitate participation, especially by developing countries. Since its inception, representatives of national statistical offices in 123 countries have participated in the Washington Group. Representatives from 89 countries have attended at least one annual meeting, and representatives from 58 countries have attended more than one annual meeting. Currently, representatives of the national statistical offices of 119 countries and territories, 7 international organisations, 6 organisations that represent people with disability, the Statistics Division of the Department of Economic and Social Affairs and other United Nations system entities are members of the Washington Group.

The Washington Group has developed a short set[[4]](#endnote-4)[[5]](#endnote-5) of questions to be used in Census and extended set[[6]](#endnote-6)[[7]](#endnote-7) of questions to be used in specialized surveys. According to information obtained from the country reports submitted by the primary country representatives during the period from the ninth to thirteenth meetings of the Washington Group on Disability Statistics, 35 countries included the short set of questions (see Appendix I), or some variant, in their recent census rounds. While countries continue to report disparate disability prevalence rates, with few exceptions, those that use the resources of the Washington Group on Disability Statistics as intended have reported disability prevalence rates that are comparable.

**World report on disability[[8]](#endnote-8)**

The World report highlights the need for greater understanding of the numbers of people with disability and their circumstances in order to work towards removal disabling barriers and planning a range of services that enable people with disability to actively participate in economic, social, civil and political life.

Key recommendations on disability data from the report are:

* As a first step national population census data can be collected in line with recommendations from the United Nations Washington Group on Disability and the United Nations Statistical Commission.
* A cost-effective and efficient approach to gain comprehensive data on people with disability is to add disability questions – or a disability module – to existing sample surveys such as a national household survey, national health survey, a general social survey or labour force survey.
* Dedicated disability surveys can be carried out to gain extensive information on disability and functioning – such as prevalence, health conditions associated with disability, use of and need for services, and other environmental factors, including on people living in institutions and children.
* Improve collaboration and coordination between various initiatives to measure disability prevalence at global, regional and national levels.

**State of the World’s Children[[9]](#endnote-9)**

Data collection in the area of childhood disability in developing countries has been inadequate to date despite the large impact that disability has on child development, family life, and socio-economic conditions of communities. The State of the World’s Children indicates that this is in part due to the lack of an established best method for identifying children with disability in this context, as well as difficulty in defining and evaluating child disability in resource-poor settings. Different methodologies have been used to collect data in different locations making comparisons across countries problematic. By incorporating the *Ten Questions Screen for childhood disability*, UNICEF’s Multiple Indicator Cluster Surveys have become the largest source of internationally comparable data on children at increased risk of disability in developing countries. The last round of the Multiple Indicator Cluster Surveys, implemented in 2005-2007, collected data on disability for 26 of 50 countries participating in the program.

The *Ten Questions Screen for childhood disability,* covers children aged 2–9 years and applying *Ten Questions Screen for childhood disability* during the 2005–2006 Multiple Indicator Cluster Surveys yielded a wide range of results across participating countries (3 to 48 per cent). Although the *Ten Questions Screen for childhood disability* comes with a recommendation that it be followed by an in-depth assessment, few countries have had the budgets or capacity to conduct the second stage clinical assessment to validate results, and they have been further hampered by the lack of a standardized methodology for conducting the assessment. For the fourth round of Multiple Indicator Cluster Surveys (2009-2011), it has been recommended that only countries that have the capacity, resources and commitment to conduct the medical assessment should include the Disability Module in their surveys.

Currently UNICEF is working in collaboration with the Washington City Group on Disability Statistics to improve the methodology used to measure child disability covering children aged 2-17. The UNICEF-Washington Group[[10]](#endnote-10) module on child functioning and disability is being developed in line with current thinking on child disability. The questionnaire covers children between the ages of 2 and 17 and assesses speech and language, hearing, vision, learning (cognition and intellectual development), mobility and motor skills, emotions and behaviours. The use of this module in future rounds of Multiple Indicator Cluster Surveys and other data collection efforts aims to produce internationally comparable data. Also in development is a standardized overall methodology for a more in-depth assessment of disability in children. This will consist of data collection protocols and assessment tools, as well as a framework for the analysis of findings. Recognizing that specialists may be in short supply in some areas, a toolkit is being designed to enable teachers, community workers and other trained professionals to administer the new methodology. This will serve to strengthen local capacity to identify and assess children with disability.

Furthermore, UNICEF and the Washington Group on Disability Statistics are working towards development of a survey module on the measurement of environment and school participation[[11]](#endnote-11). The aim is to measure the barriers to and/or facilitators of education for children with and without disability. The module will complement the module on child functioning and disability described above. Together, the two modules will provide a comprehensive measurement of disability, assessing children’s functional limitations as well as their interaction with the environment.

**World Health Organisation/World Bank collaboration on model disability survey**[[12]](#endnote-12)

The World Health Organisation and the World Bank, along with input from Statistics Norway and the Washington Group on Disability Statistics, have been working to develop the model disability survey. The survey asks respondents not only what their intrinsic abilities are, but also how those abilities play out in the person’s real life environment. In addition, it asks for details regarding the person’s built and attitudinal environments, as well as the assistive devices they have in place. Additional modules ask about health-care utilization, health conditions and well-being. The model disability survey, along with other such initiatives, will provide the data that social, health and other policies require, and thereby support countries to implement article 31 of the Convention on the Rights of Persons with Disabilities (Statistics and data collection). It is being developed in a modular format to enable countries to collect comprehensive information on disability through a national disability survey or to include relevant modules in existing data collection efforts. It is expected that, after initial testing in some countries, a short version will also be developed as a subset of the full survey that can be included in other national or sub national surveys. The questionnaire has been developed drawing on the best questions from all 179 disability surveys carried out since 2000. As such, it builds on existing work on disability data from around the world.

The Washington Group on Disability Statistics has provided expert advice on the structure of the questionnaire, the wording and order of the questions. The placement of the questions and exact question wording within the model disability survey, in particular of the Washington Group questions, has not been determined; however, both issues are important given the desire to maximize international comparability and avoid confusion at the country level.

**Second Forum Disability Ministers’ Meeting [[13]](#endnote-13)**

The Forum Disability Ministers’ Meeting was held in Port Moresby, Papua New Guinea, in October 2012. The theme of the meeting was ‘*Progressing Disability Inclusive Development in the Pacific*’. Ministers urged national and regional stakeholders to work together to increase the disability data, research, and knowledge and use this to better inform decision making. They agreed that health, disability and other relevant stakeholders must increase efforts to improve NCD-related disability data, evidence and surveillance. They sought development of a sustainable funding strategy in order to improve data collection.

**Regional Conference of Heads of Statistics and Planning[[14]](#endnote-14)**

During July 2013, Heads of Planning and Statistics convened at Secretariat of the Pacific Community Headquarters in Noumea, New Caledonia for their fourth triennial meeting. Representatives from the National Statistics Organisations, planning offices, and some line ministries of 19 Pacific Island Countries and Territories attended the five-day conference. A joint presentation on disability statistics in the Pacific was given by representatives from World Health Organisation and United Nations Children’s Fund. The presentations noted there are enormous discrepancies on disability statistics among Pacific Island Countries and Territories, with data on disability not available for American Samoa, French Polynesia, Guam, Marshall Islands, Niue, Commonwealth of the Northern Mariana Islands, Palau, and Papua New Guinea. Part of the challenge relates to data coming from non-standardised sources among the Pacific Island Countries and Territories. As a key recommendation national government agencies were requested to revisit and assess their data collection methods for adult and childhood disability in light of international standards, and consider including standard disability questions into regular household survey activities. Furthermore, National Statistics Offices have been requested to re-analyse existing census data on disability to obtain in-depth understanding of “equalization of opportunities”. On behalf of Government statisticians representing the Pacific Community, the following statement was made during the United Nations Statistical Commission held in March 2014: ‘During the 2010 round of population and housing censuses, most of our countries have included a short set, as recommended by the Washington Group and included in the current Principles and Recommendations for Population and Housing censuses’[[15]](#endnote-15).

**Regional Disability Inclusive Budgeting and Disability Statistics Workshop[[16]](#endnote-16)**

The Regional Disability Inclusive Budgeting and Disability Statistics Workshop was convened by the Pacific Islands Forum Secretariat in partnership with the World Health Organisation and the Pacific Disability Forum from 11-15 November 2013, Nadi, Fiji: The following next steps were identified during the workshop:

* Address need for further training in disability statistics at country and regional level.
* Develop Pacific expertise, for instance enabling the Secretariat of the Pacific Community to provide technical assistance to countries regarding disability data collection and analysis.

The workshop also made the following recommendations in relation to disability statistics:

* Disability should be mainstreamed in statistics strategic planning, including National Strategies for Development Statistics and the Ten-Year Pacific Strategy for Statistics. The Pacific Statistics Steering Committee would be a useful forum for further strengthening disability statistics.

**Strategic Opportunities**

1. Strategic Opportunities to support the Recommendationsof the World report on disability:
2. Country reports submitted by the primary country representatives during the period from the ninth to thirteenth (2009-2013) meetings of the Washington Group indicate that 35 countries included the short set of questions, or some variant, in their recent census rounds. Providing technical support to countries to include the short set of questions in their next census rounds could be beneficial.
3. The World Health Organisation and the World Bank, with input from Statistics Norway and the Washington Group, have been working to develop the model disability survey. It is being developed in a modular format to enable countries to collect comprehensive information on disability through a national disability survey or to include relevant modules in existing data collection efforts. Technical support to countries could be in the form of country level capacity building workshops on the use of the short set, extended set, and the model disability survey. It could also be in the form of resources made available to enable participation of Central Statistics Offices and Disabled People’s Organisations in the annual meetings of the United Nations Washington Group on Disability Statistics and technical meetings related to the development of the World Health Organisation and the World Bank model disability survey.
4. Uganda's Demographic Health Survey 2011 incorporated Washington Group’s short set of questions on disability. Including these questions in all future Demographic Health Surveys allows for a good start in defining the global disability challenge and developing appropriate policies through which the global community can contribute to disability-inclusive development. Most importantly, it will also allow for international comparison and enable the post 2015 Development Agenda country reports to disaggregate data on disability and contribute to monitoring the progressive realisation of the rights of people with disability. Promoting the use of the short set of questions in the next round of Demographic Health Survey in the Indo-Pacific and providing technical support and resources to such an endeavour could strengthen disability data collection and use.
5. The extended set of questions was adopted by the Washington Group on Disability Statistics after its tenth meeting in 2010. A subset of the extended set on functioning was submitted to Eurostat for inclusion in the European Health Interview Survey. Technical support to partner governments to enable inclusion of this subset in existing sample surveys such as a national household survey, national health survey, general social survey, or labour force survey could be beneficial.
6. Strategic opportunity to support a way forward identified by State of World’s Children report:
7. State of World’s Children 2013 highlighted that ‘reliable and objective data are important to assist in planning and resource allocation and to place children with disability more clearly on the development agenda’. The State of the World’s children presented a way forward which involves a partnership between UNICEF and the Washington Group on Disability Statistics to develop a screening tool that reflects current thinking on child functioning and disability. Supporting this partnership will allow the finalisation of tools and manuals to support measurement of prevalence of children with disability.
8. Strategic Opportunity in the area of Social Protection:
9. Asian Development Bank estimates[[17]](#endnote-17) (based on Social Protection Index country reports) indicate that while disability-specific social assistance programs collect disability data (i.e., regarding people with disability who benefit), mainstream programs generally do not. This means it is difficult to understand the coverage of mainstream social protection programs and/or their impact on people with disability. Provision of technical support to Indo-Pacific social assistance programs regarding the collection of disability data would be a way forward in ascertaining the coverage and impact of a variety of these programs.
10. An International Labour Organisation report on the social protection floor in Indonesia[[18]](#endnote-18) states that the percentage of people with severe disability covered by social assistance programs (i.e., programs open only for people with severe disability) will progressively grow from 11.8 per cent in 2012 and increase to 100 per cent in 2020. Typically, data collection efforts to establish the national prevalence of disability motivated by contemporary international classification measures of disability, such as the Washington Group Short Set, will differ from administration data collection efforts which identify persons eligible for disability programs. These are typically linked to a higher functional limitation threshold (severity) and an assessment of the capacity to work. Currently, there exists no standardized tested measure to establish higher thresholds of functional limitation as eligibility criteria for disability programs in Low and Middle income countries contexts. In the absence of a standardized measure, it is therefore not possible to measure the efficiency of targeting of Government programs in line with their obligations as laid out under international and national law[[19]](#endnote-19). This gap in knowledge needs to be addressed as a priority resulting in development of standardized measures for low and middle income country contexts.
11. Strategic Opportunity in supporting the Incheon Strategy:
12. The Incheon Strategy “Make the Right Real” for Persons with Disabilities in Asia and the Pacific was adopted in 2012. It provides the Asian and Pacific region, and the world, with the first set of regionally agreed disability-inclusive development goals. Developed for over two years of consultations with governments and civil society stakeholders, the Incheon Strategy comprises 10 goals, 27 targets and 62 indicators. In this regard, Governments are requested to establish baseline data by 2017 at the latest. United Nations Economic and Social Commission for Asia and the Pacific carried out a regional survey during 2013 on the availability of national baseline data for the Incheon Strategy. The report is yet to be published but is likely to outline availability of national data for the Incheon indicators and to outline potential capacity-building opportunities aimed at assisting National Statistical Offices and/or other governmental offices responsible for collecting, compiling and processing data for the Incheon Strategy. Consideration to provide technical support to United Nations Economic and Social Commission for Asia and the Pacific Member States to develop and implement capacity building activities will strengthen data collection in order to benchmark and monitor the Incheon Strategy.
13. Strategic Opportunity in supporting Central Statistics Offices:
14. Government statisticians representing the Pacific Community reported to the United Nations Statistical Commission early this year. The report informed that in collaboration with UNICEF and the Pacific Disability Forum (a regional Disabled People’s Organisation), and the Secretariat of the Pacific Community is in the process of analysing regional trends on disability. A report of the analysis will be provided to the Small Islands Developing States conference to be held in Samoa during September 2014. It is likely the report include gaps in data as well as technical challenges related to their use of the Washington Group short set of questions and opportunities going forward. Consideration to provide technical support to the Secretariat of the Pacific Community in addressing the data gaps and opportunities going forward could strengthen disability data collection and use.
15. The 4th Regional Conference of Heads of Statistics and Planning was held in Noumea-July 2013. The conference requested United Nations Children’s Fund and World Health Organisation to continue the dialogue and engagement with National Statistics Offices in the Pacific on secondary analysis of census data. Ascertaining the current status of the analysis plans will identify strengths for potential (south-south collaborations) and challenges in addressing technical capacity as well as resources required to commission such analysis. The conference also sought Secretariat of the Pacific Community to include disability as a theme in the National Minimum Development Indicators database. Ascertaining the strengths and challenges faced by the Secretariat of the Pacific Community in fulfilling this recommendation could be beneficial.
16. Strategic Opportunity in supporting other relevant United Nations Initiatives
17. The Department of Economic and Social Affairs of the United Nations Secretariat in collaboration with United Nations Educational, Scientific and Cultural Organisation is organising an Expert Group Meeting in July 2014 to develop policy recommendations to prompt work by the United Nations agencies and national statistics agencies to address data gaps and revise methods of data collection, synthesis and reporting, with a view to strengthening disability data collection and use. Being involved in the development of this policy and supporting the implementing of the same would enable strengthening of disability data collection and use.
18. Strategic Opportunity to SupportANCP partners
19. ANCP partners have been advised that annual development plans and annual performance reports are to provide disaggregated data by gender, age and disability. Many organisations may lack capacity and not be experienced in the collection and of disability data, this presents in providing disaggregated data on disability. Hence, ascertaining the current capacity of Non-Governmental Organisations and supporting provision of technical assistance and capacity development initiatives needs to be considered. Capacity development initiatives could include information and training sessions on validated tools for collecting disaggregated data on disability, appropriate methodologies to collect such data, analyse and interpret the same.

**Annex I: Washington Group Questions**

**Short Set:** The short set of questions on disability for use on national Censuses has been developed, tested and adopted by the Washington Group on Disability Statistics. The questions reflect advances in the measurement of disability and use the World Health Organisation’s International Classification of Functioning, Disability, and Health[[20]](#endnote-20) as a conceptual framework. The Washington Group on Disability Statistics has identified the assessment of equalization of opportunity as the purpose for measuring disability that can best be achieved in a Census. Over the course of time, the Census allows for assessment of equalization of opportunity by monitoring and evaluating outcomes of anti-discrimination laws and policies, and service and rehabilitation programmes designed to improve and equalize the participation of people with disability in all aspects of life.

The census format requires that a limited number of questions be devoted to any one statistic that needs to be produced. For the reasons of simplicity, brevity and comparability, the Washington Group on Disability Statistics made the choice to identify limitations in domains of basic activity functioning that are found universally, which are most closely associated with social exclusion, and which occur most frequently. The information that results from the use of these questions is expected to:

Represent the majority, but not all persons with limitation in basic activity functioning in any one nation.

Represent the most commonly occurring limitations in basic activity functioning within any country.

Capture persons with similar problems across countries.

For the purpose of determining disability status using census data, people with disability are defined as those who are at greater risk than the general population of experiencing limitations in performing specific tasks (activities) or restrictions of participation in society. This group would include persons who experience difficulties in one or more of the six core functional domains: seeing, hearing, walking, cognition, self-care, and communication. The recommend short set of questions identify the population with functional limitations that have the potential to limit independent participation in society. The intended use of this data would compare levels of participation in employment, education, or family life for those with disability versus those without disability to see if people with disability have achieved social inclusion. In addition the data could be used to monitor prevalence trends for persons with limitations in the particular basic activity domains. It would not represent the total population with limitations nor would it necessarily represent the 'true' population with disability which would require measuring limitation in all domains and which would require a much more extensive set of questions.

The recommended short set of questions is as follows: The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?

2. Do you have difficulty hearing, even if using a hearing aid?

3. Do you have difficulty walking or climbing steps?

4. Do you have difficulty remembering or concentrating?

5. Do you have difficulty (with self-care such as) washing all over or dressing?

6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?

The response categories for the above questions capture a range of severity of the difficulty experienced (i.e., no difficulty, some difficulty, a lot of difficulty, and cannot do at all). These response categories allow for multiple disability scenarios to be described depending on the domain(s) of interest and the choice of severity cut-off. There is more than one way to capture disability through the application of this set of core questions; resulting in not one but several possible population prevalence estimates that will vary in both size and composition. The Washington Group has recommended the following cut-off: everyone with at least one domain that is coded as a lot of difficulty or cannot do it at all is identified as a person with disability.

**Extended Set:** The Purpose of the extended sets is to measure equalization of opportunities, which is the same as that of the Short Set for Censuses. The extended sets are to be used in surveys where there is more space to ask more questions in order to identify the target population as for the Short Set (i.e. people at risk of experiencing discrimination and disadvantage in life opportunities because of limitations in one or more basic activity domains). The extended set of questions was adopted by the Washington Group after its tenth meeting, held in Luxembourg in November 2010.

**Annex 2: References:**

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