

Consolidated Reply: Recommendations of the Expert Group Meeting on developing supplementary targets and indicators on social inclusion, population, gender equality and health promotion to strengthen the MDG process

25 March 2008

Prepared by the Moderators Team

For more information please visit:

<http://cop.mdgasiapacific.org/group/escap-mdgs>

Original Query: Srinivas Tata, UNESCAP Thailand

The Expert Group Meeting on developing supplementary targets and indicators on social inclusion, population, gender equality and health promotion to strengthen the MDG process discussed key issues related to MDG achievement in the ESCAP region was held on 13-15 November, 2007.

For the benefit of new participants of this discussion group, a brief recapitulation is provided below:

This meeting was held as part of the project being implemented by ESCAP along with all regional commissions, in order to develop supplementary targets and indicators on social inclusion, population, gender equality and health promotion to strengthen the MDG process (which are areas hitherto perceived to be not well covered by existing MDG targets and indicators). This project thus draws its inspiration from the Millennium Declaration rather than the goals and targets.

The details of the project are available in a brochure which can be downloaded:

http://www.unescap.org/esid/hds/development_account/images/DA_brochure_final.pdf

The details of the expert group meeting and papers are available at:

http://www.unescap.org/esid/hds/development_account/schedule_of_meetings.asp#egm07

The recommendations of the meeting are at the following link:

http://www.unescap.org/esid/hds/development_account/ConsolidatedDraft-finalVersion.pdf

All participants are requested to provide their inputs on the implementation of the recommendations, especially the suggested indicators and . We would particularly like to have your suggestions on areas of further research and study under the project. The suggested areas in the EGM are below:

SUGGESTED AREAS OF RESEARCH AND FURTHER STUDY

- 1) Research the key challenges and the socio-economic, cultural and political implications of population ageing by studying:
 - a. the rising demand for health services

- b. growing requirement for long-term care
- c. declining family support
- d. increasing needs for social support and income and social security
- e. labour force participation of the elderly including in the informal sector
- f. the situation of older persons living alone

2) Conduct longitudinal research on the quality of life of older persons and the support systems available to them in order to track elderly well-being and enhance the evidence-base for policy making on ageing issues.

3) Research on the situation of persons with disabilities throughout the life cycle, in particular, with respect to poverty, their access to information, communication and technology, support services and environmental accessibility.

4) Research on sub-groups within the population of persons with disabilities, such as persons with intellectual disabilities, deaf persons, women with disabilities, and those in rural and remote areas.

5) Research the situation of socially vulnerable and disadvantaged groups in the context of MDGs, paying particular attention to the challenges of social inclusion and effective strategies to reduce vulnerability and promote inclusion.

6) Study the long-term sustainability of programmes funded by governments and other donors in respect of socially vulnerable and disadvantaged groups.

7) Document best practices and lessons learned with regard to the planning, implementation and assessment of policies, strategies and programmes for achieving the MDGs.

8) Document the differentials in MDG achievement in detail between social and geographical groupings, including sub-national entities, and variations between general population and among vulnerable groups, along with determinants of such disparities.

9) Study and document links between fertility and poverty (short to medium term) and relate these links to their direct and indirect impact on health and education outcomes and in turn the effect on productivity and incomes.

10) Suggestions for institutionalization of new target and indicators arrived at this project. Men's sexual and reproductive health is also an important area of study. Needs of adolescents and young people also need to be studied further.

11) Study on further evolution of health coverage, needs of ageing populations and health promotion indicators (in association with WHO). The need to go beyond sectoral interventions towards comprehensive health system strengthening.

We look forward to your inputs in the matter.

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Summary of Responses for Consolidated Reply

The recommendations report of the Expert Group Meeting on developing supplementary targets and indicators on social inclusion, population, gender equality and health promotion to strengthen the MDGs (Bangkok, 13-15 November 2007) had been circulated to the e-discussion group for feedback.

The recommendations of the report will be considered and discussed during a UN interregional workshop to share regional findings on strengthening social inclusion, gender equality and health promotion in the MDGs planned later this year for the project. Consideration will also be made as to how the recommendations can feed into and advance indicator work in these areas of the MDGs through various UN bodies, mechanisms and forums.

The following are key highlights of the resulting discussion.

Implement the MDGs taking into consideration subgroups and disaggregated analysis:

- It is important to ensure the MDGs are implemented taking into consideration disaggregation by various subgroups. Disaggregated analysis by these various groups is needed and should be integrated in all research activities. .
- Disabled women and the disabled were cited as an example of an important subgroup. Other important subgroupings cited include older persons, youth and geographical factors such as remote (rural/outer island)
- Women do not comprise one heterogeneous group. There are many subgroups of women based on ethnicity, disability, class, religion, minority status, women from different socioeconomic classes, etc.
- Examples of areas where disaggregated analysis would be very informative: studies on the use of contraceptives, prevalence of NCDs and other health risk factors.

Collecting data on disabled women and disabled persons: Key challenges and defining disability

- A key challenge to data collection on disabled persons is unclear definitions on who is disabled and what constitutes a disability. Recent Somoan experience with 2006 Population and Housing Census illustrated this.
- Definitions for the disabled vary across countries based on different criteria. Establishing uniform definitions on the disabled is complex and not easy to find consensus on.
- The concept of disabled has developed and evolved over time. The following were reported during the discussion as some examples of its historical development:
 - a) Original traditional concept of disability: based on defining disability on the basis of one's physiological, intellectual or psychiatric conditions considered "abnormal" by doctors and professional eyes.
 - b) Rise of civil rights consciousness among persons with different disabilities draws people's attentions to the lack of enabling environment for disabled and societal and environmental flaws (ie. Inaccessible infrastructure for the disabled, lack of

information, lack of devices, attitudinal bias against persons with disabilities, rigid notion of what is "normal.").

- c) Current concept of disabled: increasing global consensus that disability is not a static attribute of an individual but a dynamic condition which results from an interaction between one's condition and environment. This is reflected in the Convention on the Rights of Persons with Disabilities which was adopted in 2006 and is now being ratified by many countries. Disability is also approached from a wider perspective paying attention to the societal, environmental, attitudinal and institutional barriers.
 - d) An underlying notion is that the disabled's impairments coupled with various barriers hinder the disabled's "full and effective participation in society on an equal basis with others".
- Different countries have different criteria for defining the disabled. Definitions for the disabled are set out in a number of countries' ordinances and laws [see detailed discussion for official definitions in Hong Kong and Korea].
 - Some factors affecting how countries establish definitions for who are disabled are:
 - a) What is the definition to be used for? For example, to decide who is eligible for public assistance, services and/or cash.
 - b) To allocate resources efficiently for those "who really need assistance" when limited resources are available.
 - c) Classification of a person as disabled is contingent on certification by medical doctor or other pre-conditions in a number of countries.
 - d) To reduce disability fraud (people fraudently report to be disabled to gain disability benefits) which was reported to be a problem in some countries.

Other issues raised on disability statistics and the MDGs:

- To implement the MDGs, the extent of poverty experienced by "persons with disabilities" can be measured on the basis of disabled/impaired people defined by social welfare related laws or by anti-discrimination law. Further clarification on this measurement could be useful.
- The issue of social disability was raised. Many people experience impairment/disability due to discrimination based on gender, race and caste, ethnicity. Is there scope for incorporating this element in current definitions of the disabled?
- Should disability be defined on the basis of physical impairment only, or on the basis of an individual's ability to not live or to live a normal life? Should someone with a physical impairment, but still living an active, normal life be considered disabled?
- On the issue of the elderly, should those experiencing blindness, hearing loss or osteoporosis usually characteristic of old age be considered disabled, though many of them remain active?

Current and key works on disability statistics

The International Classification of Functioning, Disability and Health (ICF) provides a key framework for statisticians and policy makers for disability statistics.

The UN's General Assembly resolution 62/127 highlights the need to reinforce the disability perspective in the MDGs. A report on this issue will be considered during the 63rd session of the General Assembly in autumn 2008.

Countries and national statistical offices developing their statistical capacity building in disability statistics may be interested in the UN's 2010 Programme on Population and Housing Censuses which includes recommended tabulations on "human functioning" relating to disabilities. Draft census recommendations can be accessed at:

http://unstats.un.org/unsd/demographic/sources/census/2010_PHC/default.htm.

The Washington Group and ESCAP are working on creating a workable set of questions for the census and survey to capture persons with disabilities and their socioeconomic status.

Announcements and upcoming meetings

A Regional Workshop on Promoting Disability Data Collection through Population and Housing Census is scheduled from 8-10 April 2008 in Bangkok, Thailand. The workshop is being organized by the UN Economic and Social Commission for Asia and the Pacific. For more information on the workshop, contact Ms. Aiko Akiyama, UNESCAP Subprogramme on Disabilities, telephone: (66-2) 288-2315, email: akiyama@un.org

The Washington Group will be meeting on disability statistics in Manila, Philippines. (2008 date and exact venue is still to be determined).

Recommended resources cited during discussion

interRAI

This organization is a collaborative network of researchers in over 20 countries committed to improving health care for persons who are elderly, frail, or disabled. It makes available comprehensive disability assessment tools, as well as ADL and other criteria to assess disability. Hearing and Visual problems are also included in this tool. Official website is: www.interRAI.org.

UN Economic and Social Commission for Asia and the Pacific, Statistics Division
Draft Technical Manual on Disability Statistics (2006). Proceedings; Fourth Workshop for Improving Disability Statistics and Measurement, Bangkok, Thailand, 20-22 June 2006. Access at: <http://www.unescap.org/stat/meet/widism4/index.asp>.

The UN's **2010 Programme on Population and Housing Censuses** includes recommended tabulations on "human functioning" relating to disabilities. Draft census recommendations are available at: http://unstats.un.org/unsd/demographic/sources/census/2010_PHC/default.htm".

Responses in Full

Dear Srinivas,

Congratulations on a great job of pulling the report and recommendations together! It reads very well and reflects the work that the expert group and your team put into it.

I have just one comment on the MDGs related to women's issues. Although the point is made somewhere that 'women' include women with disabilities, when it comes to the actual supplementary targets and indicators, there is no mention of women with disabilities. I do not mean to say that wherever 'women' appears, you need to add 'including women with disabilities' - that would be very repetitive. But in some titles, it may be necessary to add that. For example,

II. PROPOSALS FOR MDG 1

1) Property and Inheritance rights of women (including women with disabilities)

IV. PROPOSALS FOR MDG 3

1) Women in decision making(including women with disabilities)

If this change can be effected wherever appropriate, it would be good.

With regards,

Maya Thomas

Dear Maya,

Many thanks for your thoughts and comments on the report and recommendations, and for the good point with regard to the MDGs and women's issues. Your point is one which we also feel is important to emphasize, and we will incorporate reference to women with disabilities in the recommendations on the diversity of women's situations . It will be a good opportunity to highlight that women do not comprise one heterogenous group but that there are many subgroups of women (based on ethnicity, disability, class, religion, minority status,women from different socioeconomic classes, etc) - all these differences should be taken into consideration, and we will stress the need to address the needs of disabled women.

Thank you for the comments.

With regards,

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Hi all,

Yes - this kind of disaggregation recommended should be implicit and integrated into all the research activities so specific topics (such as - um - unmet need for family planning or prevalence of NCDs and other health risk factors) should be examined in terms of overall access/levels or whatever is appropriate for the topic and in terms of the different groups highlighted during the expert meeting discussions - disabled, older persons (perhaps contraceptive use isn't a good example - but the older age groups contraceptive use), youth (well - for Pacific region analysis this is important), remote (rural/outer island) groups (and all the others highlighted in the report). To state the obvious gender analysis is also implicit.

Kim Robertson

thank Marie.

Osama Rajkhan.

Hi everyone,

About the topic of disabilities, we asked a few questions in our Population & Housing Census in 2006. To share our experience, we experienced many situations where it was very difficult for us to define which persons are truly disabled in the total population.

For instance, where do you group people who are normal like most of us but need reading classes due to short-sight??? If we define them as visually impaired, shall we group them in the disabled persons as a whole???

Another example is someone who lives a normal life without difficulties but this person is a hunchback, where would you classify this person, disabled or not disabled???

I agree it is good to include disability but we must also agree on some uniform definitions as I just shared some difficulties we faced in our last census.

Malaefono Faafeu Taaloga

In my opinion disabled relates to immobility as we often see in older persons who have difficulty in motion and are often confined to bed/bedridden. A politically correct term

would be special needs in the case of older persons such as blindness, hearing loss or osteoporosis ("hunchback"). However the latter are not totally disabled compared to the former because they are not totally "disabled" and can enjoy a certain degree of ability e.i. they can still remain active in their old age. Food for thought.

Best regards

Dr Nugroho Abikusno, MD, MSc (nut), DrPH
(on sabbatical leave)
InResAge Jakarta
Faculty of Medicine
Trisakti University

Thanks for sharing your thoughts because for us working in statistics definitions are very important and must be very clear before collecting data. I'm glad we shared the same definition.

cheers.

Malaefono Faafeu Taaloga

Dear Fono,

The definition of disability will differ from country to country, based on different criteria that are specific to a given country. In general, the definitions are based on criteria to decide 'who really needs assistance'. For example, In India, the government has definitions for the purpose of issuing concessions and other benefits, based on the type and degree of impairments. Obviously it is important to do this in the case of developing countries with limited resources. This way, disabled people with moderate and severe degrees of impairment who are in need of assistance get included in rehabilitation programmes, and those with mild impairments and disabilities do not.

Regards to all,

Maya Thomas

Dear all,

I guess that like almost anything, it is difficult to come to a clear-cut definition. However, with reference to specific applications e.g. for qualifying a public service, one should always have an operational definition. Likewise for defining disability for the purpose of granting a service, for kind or for cash, the line to take is to balance the definition applicable to reality living with resources available. Thus, for Hong Kong, disability is necessarily certified by a medical doctor (or a psychiatrist for mental disability) with an indication for the degree of severity, then cash benefits/services are worked out and controlled by the social welfare department. So this process also involves if an individual would actively choose to accept the status as well.

Hope this is helpful.

Alfred

Dear Fono,

In terms of your questions on inclusion of people who need reading glasses, and people with "hunchback", for the former, in many countries, typically, they are not categorized into a group of "impairment" based on an assumption that glasses are readily available. For the people with "hunchback," they might have some difficulties, as I heard from some, as they have spinal bifida (spelling unsure). For example, in my county, Japan, they are categorized in to one of the impairment category. I am sorry that I forgot which country you are from. If you can communicate with me and we can talk about more on how to improve your country's disability data collection in details. We are planning on having a meeting on disability data collection in April with an initiative of our Stat division here for your information.

Regards,

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Hi everyone,

I appreciate everyone's discussion on the definition of disability and an expressed need for operational and practical definitions.

Definition of disability is really a topic of heated discussion within the disability community and it is a complex issue in many respects. First of all, there is a history on the concept of disability. Traditionally, disability was defined only as one's physiological, intellectual or psychiatric conditions, which were considered to "abnormal" by doctors and professional eyes. Then the rise of civil rights consciousness among persons with different disabilities drew people's attention to the lack of societal and environmental flaws (ie., inaccessible infrastructure, information, lack of devices, attitudinal bias against persons with disabilities, rigid notion of what is "normal."). So, currently, global consensus is that disability is not a static attribute of an individual but a dynamic condition which results from an interaction between one's condition and environment. This thinking is reflected in the purpose quoted below in the Convention on the Rights of Persons with Disabilities which was adopted in 2006 and being ratified by many countries now:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Notice, that this is not even included in the definition part of the Convention, but in the purpose section, and it says that "persons with disabilities includes," but it does not limit to this particular description. This is a reflection of how contentious the definition issue is and this is the place where global discussion finally agreed on placing a phrase on definitive description of a disabled person.

So, the question now, is how you define the disability at an operational level in a given country or an area?

Based on the new paradigm of a disability, policy makers, professionals along with persons with disabilities are first asked to look at the disability in a wider perspective, paying attention to the societal, environmental, attitudinal and institutional barriers. International Classification of Functioning, Disability and Health (ICF) provides a framework for statisticians and policy makers can work on. Currently, Washington Group and ESCAP are working on creating workable set of questions for the census and survey to capture persons with disabilities and their socioeconomic status.

When we talk about "disability," practically, we are on one hand, looking at persons with different types of impairment, be in physical, sensory, or internal. As many of you said, the government have to categorize a certain group of people with certain "impairments" as beneficiaries of social pensions, assistive devices etc., This endeavor itself varies from one country to another as different countries have different political, cultural and social histories. Some countries have a distinct category of persons with autism while others

not. Some mix up persons with intellectual disabilities with persons with psycho-social disabilities, by simply using a term "mental disability." Some also fail to see persons with multiple impairments. This obviously raises a question of comparability of data.

On the other hand, one also needs to look at the "disability" side of it. In Hong Kong, China, the Disability Discrimination Ordinance defines disability as follows:

section 2(1) of the Disability Discrimination Ordinance ("DDO"), a disability means:
total or partial loss of the person's bodily or mental functions;
total or partial loss of a part of the person's body;
the presence in the body of organisms causing disease or illness (such as HIV/AIDS);
the presence in the body of organisms capable of causing disease or illness;
the malfunction, malformation or disfigurement of a part of the person's body;
a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction (e.g. learning difficulties); or
a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behavior.

A disability includes not only a disability that presently exists, but also a disability which previously existed but no longer exists, or which may exist in the future or which is imputed to a person.

Under this definition, persons with facial disfigurement, persons who used to have impairments, would come under the disability.

Recently adopted Korean legislation defines disability as follows:

'Disability,' with respect to a cause of discrimination prohibited by this Act, means an impairment or loss of physical or mental functions that substantially limits an individual's personal or social activities for an extended period.

When we want to measure the MDG implementation, for example, extent of poverty experienced by "persons with disabilities," are we measuring persons with impairments that are defined under the mostly social welfare related laws or those which would also come under the anti-discrimination law?

One can say that measuring persons with medically perceived impairments might still underestimate the extent of "disability" in under-poverty line population, under educated population. They another might say, we would better start when we can start, that is to first measure persons with different impairments.

I guess, when coming up with MDG indicators from disability perspective, we would need to include some explanation of the issues of disability definition later on.

Discussion continues. Thank you.

Aiko Akiyama

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Hi Friends,

I will just share here that in Pakistan we have not any disability percentage available. In this way a person who has a very low impairment or just a very low level permanent deficiency claims same right as any person have severe or multiple disability or high percentage of impairment. In such condition as that person have very very low impairment enjoys all the facilities and rights in compare with that Person with Disability that have high level of impairment. Developing countries like Pakistan we face some other discrimination's that is rural and urban based PWDs or remote and urban based PWDs. All major Government facilities are available in urban areas and almost all INGOs or Developmental agencies also work in particular limited area.

We PWDs in developing countries also face discrimination through disability frauds. Because here is no check and transparency on disability. Some person has very low visual impairment that person acts like totally blind. Many criminal play dramas to save then selves act like person with intellectual Disability. They often succeed because there is not proper facility to check such fraud or bogus disability claims.

Regards

Ghulam Nabi Nizamani
President All Sanghar Handicaps' Association (ASHA)
PAKISTAN

Dear Srinivas,

Many thanks for sending along these documents and links. They are especially informative since I was unable to attend the EGM. I'm also following with interest the discussion on gender and disability and look forward to staying in touch on this.

Best regards,

Anjana
Anjana Bhushan
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Thanks Aiko for your help,

Yes I am interested in the disability definitions because we as Statisticians and Data collectors need "accurate and specific definitions" in order to collect the correct data. As we are collecting and comparing data to achieve the MDG we need to know these data differences in other countries. For me, if all countries have different definitions of "persons with disabilities" then the question is, are we achieving the same MDG???? It is the same question with other indicators not just disability.

However, I am glad that the group have shared their country experiences and definitions which of course helped to broaden our knowledge of what is happening in other parts of the world.

We are in the process of preparing our Disability Survey in SAMOA (small island in the South Pacific for those who don't know) hence our interest in finding out information on disabilities is important.

cheers,

Mrs Malaefono.Taua.F
Assistant Chief Executive Officer
Census/Surveys/Demography/Social Statistics
Statistics Department
Ministry of Finance.

Hi Everyone,

Regarding to specific definitions of disability, you can visit this website, <http://www.interRAI.org>. It is official website of the interRAI, this organization is a

collaborative network of researchers in over 20 countries committed to improving health care for persons who are elderly, frail, or disabled. They held meeting in Bangkok three weeks ago. I had opportunity to discuss with one of experts in this group. He showed us the disability assessment tools, which quite comprehensive. It use ADL and other criteria to assess disability. Hearing and Visual problems are included in this tool, too. He also said that there is no fee for using this tools for government. We in Thailand plan to assess demand and supply for long term care in our country. Therefore we are very interested in this tools. However, I cannot mention about its accuracy or validity. Just for your information!

Regards,
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Dear Members,

The definition focuses only on the physical disability. What about social disability. Discrimination based on gender, race and caste, ethnicity is a major problem that millions of people face world over. Is there a scope to bringin this element while defining the 'disable'.

Regards,
Ramaiah
www.tiss.edu/faculty/ramaiah

Statistics ESCAP has prepared, to my mind, a good draft technical manual on disability statistics; here is a bibliographic reference from a monograph I did some time ago on BMF monitoring and Internet resource link:

_____ (2006). Proceedings; Fourth Workshop for Improving Disability Statistics and Measurement, Bangkok, Thailand, 20-22 June 2006 – available at <http://www.unescap.org/stat/meet/widism4/index.asp>.

Attached is latest thinking of UN system on measuring MDGs, in which persons with disabilities are significant by continued absence.

However, UN GA's 62nd session (2007) adopted a very strong resolution on need to reinforce disability perspective in MDGs process and will consider a report on the question at it autumn 2008 / GA63; GA res 62/127 is attached.

One option to consider when pursuing improved disability statistics in countries is to take a meeting with the national statistical office or similar body and discuss their plans for participating in UN's 2010 programme on population and housing censuses, which include recommended tabulations on "human functioning". Here is the Internet link: http://unstats.un.org/unsd/demographic/sources/census/2010_PHC/default.htm. Draft census recommendations are a large download but worth the effort.

Best regards – Clint Rapley

Hi,

Thanks Clinton.

FYI.

Stat division here, in collaboration with the disability subprogramme, will organize the regional workshop on promoting disability data collection through population and housing census from 8 to 10 April this year here in BKK. At this workshop, we will go over the ICF-based approach to disability data collection, identify gaps between the currently existing data and data needs by policy makers and disabled people and explore survey questions (disability specific or add-on etc.). As I understand, they would choose the pilot project countries to test survey questions. Later on this year, the Washington Group will have a meeting in Manila, the Philippines to work on an extended set of questions. Should anybody be interested in coming to the meeting, let us know.

I look other comments and get back to you.

Regards,

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<http://www.unescap.org/esid/psis/disability/index.asp>

Dear Aiko Akiyama

Much pleased to know that you would organize a regional workshop on disability to promote data collection on disability. As you would guess, I would be much interested to take part in it. Would you please advise on this.

Dr Sharifa Begum
Senior Research Fellow
Bangladesh Institute of Development Studies, Dhaka
