

**Washington Group on Disability Statistics (WG)**

**Draft position paper on extended disability measurement set(s)**

**Version 9 September 2004**

**DRAFT**

# 1 Introduction

*by Marijke de Kleijn*

*This part should deal with:*

- *objectives of WG*
- *general measure versus extended measure*
- *with reference to existing papers*
- *ICF as the framework*

During the Brussels meeting last February we decided to create a Workgroup 3 in order to “prepare a position paper proposing an approach for the development of extended measurement set/s related to the general disability measure/s”.

Members of Workgroup 3:

Carlotta Besozzi, Euroforum

Don Lollar, USA

Gunilla Davidsson, Sweden

Emmanuelle Cambois, France/Euroreves

Ros Madden and Xing-yan wen, Australia, AIHW

Ken Black, Australia, ABS

Marijke de Kleijn, Netherlands, convenor

Nenad Kostanjsek and Somnath Shatterji have been informed and invited to send comments.

In order to prepare the paper on time for the Bangkok meeting the convenor developed an outline of the paper and a tight timetable. The members agreed with the timetable and commented the outline. A revised outline was sent to the members including names of persons responsible for a chapter and the potential content of each chapter in key items. The contributions by the members were combined into one paper. There was no time for an overall discussion by the group based on the complete paper. So the content should be seen as food for discussion, not as a set of proposals agreed by the work group.

## **Proposal**

To discuss this draft paper and decide for each chapter how to proceed by who and when.

## 2 Purpose of extended sets

by Xing-yan Wen, AIHW

*This part should include:*

- *which purpose for internationally comparable disability data to be collected by extended measurement set(s) do we want to serve; preference for same (chosen) purposes for general measure (see paper and report WG3 meeting)!?*
- *To be taken into account: work done by AIHW*

The equalisation of opportunity is the fundamental goal for people with a disability. To consider this goal as relating to the purpose for general measures for census (Workgroup 1) is to ensure that the questions identify a broad subpopulation group containing as many people with a disability as possible, and that the data collected are comparable across countries.

### **Proposal**

Keep the same purpose for the general and the extended sets.

If this proposal is accepted it may be necessary to consider some specific additional purposes to assist in the development of extended questions for surveys. There are a number of issues relating to the extended sets of questions which require us to identify, and agree with, some specific purposes as guidelines:

- \* We need to consider why we need these extended sets, what the limitations of the general questions are, and what is needed in the extended questions. To identify some specific purposes may assist in resolving issues discussed in Chapter 3 on relationship between general and extended questions, for example, whether the extended sets of questions should be used together with the general questions as part of the data collections or as a follow-up survey where the general questions are used as screeners.
- \* To agree on some specific purposes may also facilitate the work in various subsequent chapters, in particular chapters 4 and 5 at this stage, as these chapters address various technical and context issues. For example, different sets of questions may be developed for different specific purposes (Chapter 4); when existing/recommended items/questions to be examined (Chapter 5), they need to be considered in relation to specific purposes identified and agreed in Chapter 2.
- \* There are multiple specific purposes for the use of the general questions as well as the extended questions. To tailor the extended questions to some specific purposes may assist statistical systems of individual countries in justifying the collection of disability data using these measurements in light of limited resources and competing demands regarding issues of national priorities for different countries.
- \* We have a clear emphasis on the international comparability in designing both the general questions and extended questions. Nevertheless, we may need to consider some

flexibility with the extended questions, which enables individual countries to meet their special needs. For example, we may consider a core set of questions which can ensure the comparability, and several variations from the core set for specific purposes of individual countries.

- \* The ICF framework encompasses the complex and multi-dimensional experience of disability. It is not possible for the general census questions to cover detailed domains of various dimensions of the ICF. The extended questions may cover more detailed domains for specific purposes.

- \* We need to consider what we are really going to measure in terms of the components of the ICF. Is it necessary to have different focuses in terms of the ICF components between the general census questions and the extended survey questions?

- \* We suggest to clearly state that the implementation of ICF in disability data collections is one of specific purposes. In fact this is one of the main purposes for establishing the WCG. If the workgroup agrees that we should discuss specific purposes in Chapter 2, further work may include:

- \* To list potential specific purposes for the extended sets of survey questions;
- \* To make recommendations for prioritising the potential specific purposes; and
- \* To consider the relationship of specific purposes and the issues in various subsequent chapters.

### 3 Relationship general and extended

by Gunilla Davidsson

*This part should include issues such as:*

- *are we talking about the extend of functioning/disability using certain indicators or do we also want to measure the type of functioning/disability and the type of environmental barriers/facilitators?*
- *extended measure more detailed info*
- *related to general measure or not (preference: extended measure to be a more detailed indicator allowing to move towards a higher level of measurement as outlined in paper WG3.6a*
- *extended set as a follow-up after the general measure as a screener*
- *extended set used in a separate study in order to know the content of the general set*
- *extended set can be seen as a more detailed indicator or as an information source for separate items included in the set*

#### **General and/or extended items**

One or two general questions might be used to measure disability in a population or as screeners in order to get a sample frame of disabled persons for a separate survey. Data source is most often the census or a large sample based national survey.

Extended sets of items/questions might consist of a few additional questions in a census, a module in a survey on another subject than disability or an independent survey (short or comprehensive).

#### **The general question as a condition to extended sets of questions**

The phrasing of the general question(s) WG will recommend, will also govern the extended set or sets of items WG will produce and offer.

*Examples:*

A general question like the one used by Eurostat in the Minimum Health Module (MHM) – “Do you suffer from any long-term or chronic disease?” – will need an extended set of questions to assure that the “right” groups of disabled persons are included.

A general question like the following (based on a WHO question) used by Statistics Sweden, has a quite different approach and another type of shortcomings. – “Now we have some

questions to disabled people. By disabled people we mean persons with reduced vision or hearing, speech- or voice problem, mobility problems, allergy or any type of psychological problems. You can also have diabetes, a heart- or lung disease, stomach-bowels disease, psoriasis, epilepsy, dyslexia or something similar. According to this definition, do you belong to the group with disability?" A question like this is very time-consuming (which is just one of the shortcomings).

A third type of general question is used by Statistics Canada and the Australian Bureau of Statistics. They have very broad questions with a rather "vague" phrasing which seems to be the best way to catch the intended groups of disabled persons in those countries. But this type of broad and vague question still needs to be tested in other countries to see if it can be used as a general question recommended by WG.

### **Which type of extended sets of items should WG try to come up with?**

Our ultimate goal ought to be to fulfill as many needs and demands as possible. This means that we have to develop more than one extended set of items (and finally reference questions in English) to use either as follow-up after a general measure or as an independent module or survey.

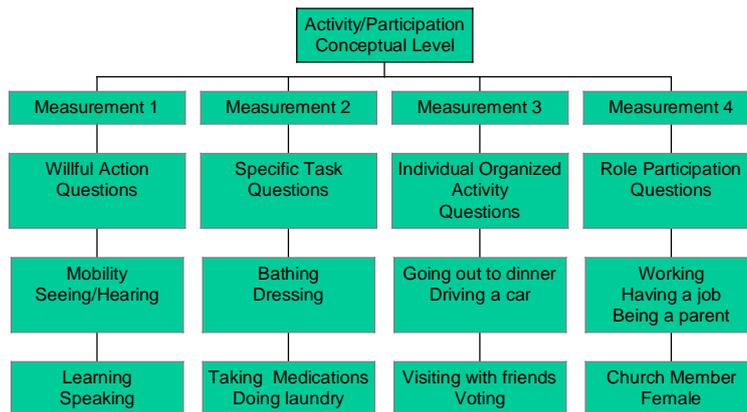
The extended items have to fit different needs in different countries. A country recently suffering from war or any other major catastrophe (earthquake etc) is probably having a quite different need of extended items than a country which regularly runs a health survey and now wants to use the new ICF concepts for comparative reasons. And according to which type of extended set of items is used the field of application varies:

- to get a broader general information by more items which all are separate sources of information
- to get a more detailed information about an existing variable/indicator
- to use extended items in order to create a new more detailed/complex variable/indicator

This means that we are talking both about extended items on functioning/disability and items for capturing activity and participation. We are also talking about to come up with extended sets of items that are adapted to or harmonized with the ICF concepts.

The following figure from paper WG 3.6a can serve both as a tool and a goal in our work when it comes to questions about activity and participation. The goal is of course to fill as many “boxes” as comprehensive as possible.

### Transition from the Empirical Representation to the Measurement at the Observational Level



#### One way to reach the goal

WG will have to create a data bank with extended sets of items to be recommended in different contexts. And also offer references to means of translating the questions, keeping the content at the same time as taking care of cultural and language discrepancies (= no literal translation).

The extended sets of items should be constructed in order of rank, starting with the most important and overall indicators. If the countries keep the ranking when introducing new items, the most important variables/indicators will in due time be comparable for many countries around the world.

The degree of detailed information that will be comparable around the world is depending on how comprehensive extended sets of items WG will work out for recommendation.

A big task for WG will be to decide upon which extended sets of items or which “boxes” will have the highest priority. Another big task will be to collect validated questions, select the possible ones and have them tested cognitively to assure they are usable all around the world.

Below is an example (using only three countries) of a rather “simple” item, but still there will be several considerations to make in deciding which items to rank, in which order and which questions to recommend.

***Example: Hearing***

**Items to be ranked:**

*Minor* hearing problem  
in group conversation

*Major* hearing problem  
in group conversation

Hearing problems *in noisy*

**Examples of questions from surveys in Canada,  
Denmark and Finland:**

Are you usually able to hear what is said in a group conversation with at least 3 other people without a hearing aid?

Are you normally able to hear what is said in a normal conversation between 3 persons or more (with hearing aid if normally worn) with no difficulty with minor difficulty, with major difficulty or not at all?

Can you without difficulty hear what is being said in a conversation among several people? (with or without a hearing aid)?

Are you usually able to hear what is said in a group conversation with at least 3 other people with a hearing aid?

Are you usually able to hear what is said in a conversation with one other person in a quiet room without a hearing aid ?

Are you usually able to hear what is said in a conversation with one other person in a quiet room with a hearing aid?

How do you hear talk/speech in a noisy or sonorous

surroundings

surrounding:

I hear without difficulties

I can hear, but there are problems discern speech  
very poorly or not at all?

*Severe* hearing problem

Are you able to hear at all?

### **Usefulness**

It is obvious that the usefulness of standardized (in context) extended sets of variables/- indicators will fulfill many functions at the same time. We will get comparability between a lot more countries than today, the ICF concepts will (“automatically”) be introduced and used, each country will save time and money by using “ready-made” sets of variables/indicators and research on an international level will be provided with data of much better quality than today.

### **Proposal**

- The Washington Group has to decide upon continuing in developing one set of extended questions or more than one at the same time.
- We prefer the development of one at the same time.
- The WG should decide which kind of sets should be developed (impairment + basic activities versus complex activities + participation)
- Or start with one set of extended questions (not too few nor too detailed) covering all areas (physical, mental, social); the first set can serve as a starting point for more detailed questions or for additional sets in the future.
- If there is a strong wish for a set of extended questions adapted especially for countries which have suffered from wars and where priority for more specific data is high, we could have two parallel working groups from the beginning.

## 4 Required characteristics

by Ken Black, ABS

*This part should include issues such as:*

- *description of existing experience and a proposal how to include this in our work*
- *related to ICF concepts, terms and codes (choice of domains)*
- *nature and scope of extended sets*
- *fit into sample based population surveys (lay interviewers) without HES*
- *including “mental” issues*
- *enough expected numbers for the items in sample based population surveys*
- *attention for children, elderly*
- *attention for possible use in institutionalized population*
- *sets as “indicator” versus set of items which are interesting on its own (core versus longer list?)*
- *“can” versus “do” option (capacity versus performance)*
- *different items/sets for different purposes and settings?*
- *proposal to work on two sets: one for function/structure cq impairment and basic activities cq activity limitations, and one for complex activities (limitations and participation (restriction) and environment?*
- *criteria and methodology for item reduction*
- *take into account work done by Euroreves and ABS*

This section of the paper aims to describe desirable characteristics of a population survey instrument (or an extended module) designed to produce statistics about people with a disability. The ideas are based on experience gained by the Australian Bureau of Statistics (ABS) in conducting national disability surveys.

### **ABS disability survey 2003**

In Australia, the most recent national disability survey, conducted in 2003, involved a multi-stage, stratified, random sample of some 40,000 people. Data was mainly collected by interviewers, using computer assisted interviewing (CAI) techniques. A mail-out mail-back method was used for people who live in cared accommodation (ie those in the institutional

sector). The questionnaires for people in cared accommodation forms were completed by staff at the selected establishments.

Interviewers were selected from the ABS labour force interviewer panel and provided with three days of survey specific training. Most interviewers would not have had any formal medical training. The average household interview time for the survey was 44 minutes, with the longest being nearly five hours. The sample size allowed for detailed tabulations to be released at the national level and for very broad geographic areas. Data for small geographic regions or for small population sub-groups (e.g. those with less common rare types of disability) are not released due to sampling errors associated with the estimates.

For the 2003 survey a set of 17 screening questions were used to help identify people with a disability. Based on the ICF, the questions cover most domains in the body function, activity and participation components of the ICF, and also include questions related to the 'products and technology' and 'support and relationships' domains within the environmental factors component. As such they refer to various impairment types, activity limitations, participation restrictions, the need for assistance, specific health conditions and peoples use of aids and equipment. They are designed to identify as many people with a disability as possible within enumeration constraints. Screening questions which are general in nature e.g. 'whether any household member has chronic or recurrent pain or discomfort?' are followed by a second stage filter of 'whether the person identified is restricted in everyday activities because of the pain or discomfort?'

In practice the screening questions are asked of the first responsible adult in households selected in the sample. This respondent is asked to answer the screening questions for themselves and all the other people with whom they live. People identified by the screening question are referred to as being in the output 'disability' population and are each individually selected for a personal interview. These people are then asked a more detailed array of questions, many involving further ICF related concepts. It should be noted that some countries, such as Canada and New Zealand, do not use this approach. Rather they use census data to target the sample for a subsequent disability specific survey.

## **ABS list of characteristics**

The following points list characteristics, or design features, of the Australian disability survey that might be used in other contexts:

- 1 The design must serve key user information requirements, align with ICF concepts, and be cost effective.
- 2 The questions should cover various ICF components and domains so that: all people with disabilities of interest can be identified, counts of people with disabilities can be aggregated and disaggregated in a variety of ways to meet different user needs. This includes providing a means of categorising people by type and severity of disability. Sub-groups of key policy concern can be separately identified
- 3 Interview questions should be designed for use by interviewers accustomed to doing household surveys but with no formal medical training. Question wording should be concise and use simple language to ensure that all respondents can readily understand what is being asked
- 4 To obtain a good understanding of the nature of the disability the survey should seek to obtain information about underlying medical conditions. (Note: in the ABS disability survey, for each screening question, whenever a person is identified as having a disability, they are asked a further question to identify any underlying medical condition and responses are coded to a collapsed version of ICD10).
- 5 Combinations of questions asking about specific limitations/restrictions can be used to help identify individuals with a disability. Questions which are general in nature e.g. 'whether any household member has chronic or recurrent pain or discomfort?' should be followed by a second stage filter of 'whether the person identified is restricted in everyday activities because of the pain or discomfort?'
- 6 Questions should as far as possible be used to identify mutually exclusive groups however to help ensure all people of interest are included.

7 Constraints on interview time, respondent burden, and overall survey budget including processing and output will also have an impact on the extent of component/domain coverage.

8 A question on 'receipt of treatment or medication' should be included, after all other screening questions, to help capture people not identified as having a disability with the more specific screening questions.

9 Additional questions should be used to help ensure the identification of people with a mental illness. A specific question: 'need for help or supervision due to mental illness or condition' should be included. Note: those with a mental illness can also be identified from the question on 'receipt of treatment or medication' if the follow-up question on underlying cause is asked.

10 When asking about very young children (0-4 year olds) appropriately modified question wording should be used to ensure that children with 'real' activity limitations /participation restrictions etc are correctly identified.

11 Consideration should be given to asking older people additional questions to help identify those with a disability. (Note: Australian experience has shown that when people aged 60 years and over are asked the well established Instrumental Activities of Daily Living IADL activity limitation questions (e.g. meal preparation, housework, paperwork, transport etc) many are identified as having a disability even though their responses to the standard disability status screening questions informed that they did not have a disability. Testing has shown that a significant proportion of 'older' people view themselves as being 'the same as everyone else their age' and so do not associate with general questions on impairments and/or limitations or restrictions but will respond to very specific questions on limitations or restrictions in specific domain areas.

12 The questions should be concerned with what people do/don't do, in their own environment and not some hypothetical circumstance to identify their disability status. (Note: the ICF draws a distinction between 'capacity' (what a person can do in a uniform or standard environment) and 'performance' (what a person usually does in their own environment) to help identify a person's disability status. For interviewer-based or self-completion household

surveys, the 'performance' approach is recommended. It is easier to obtain information about what actually happens than what could theoretically happen).

13 Surveys focussed on people with disabilities should, where possible, not be restricted to private households but also include people in cared accommodation (i.e. in the institutional sector). While the institutional sector may only represent a small share of the total population a large share of people with a more profound disability may be living in cared accommodation (in Australia nearly 30% of the population with a profound disability lived in cared accommodation).

### **Disability module**

In Australia the 'disability module' used in some social surveys uses a collapsed version of the disability screening questions used in the national disability survey. It includes a shortened version of the questions on activity limitation/need for assistance in the core activity areas of self-care, mobility and communication to provide a measure of level of severity. While the question set is smaller a design principal is that the groups being measured are conceptually consistent with the larger set and also consistent with the ICF.

A copy of the disability module is provided attached.

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See for further information ABS Web Site: [www.abs.gov.au](http://www.abs.gov.au)

### **Proposal**

To discuss whether the Australian issues are relevant for our work and if so how to apply.

## 5 Existing/recommended items/questions to be taken into account

by Marijke de Kleijn

*This part should include issues such as:*

- *Description of existing material and proposal how to use this for our work*
- *UN guidelines*
- *WHO ICF checklist annex 9*
- *EURO-REVES recommendations*
- *Eurostat, OECD, WHO-Euro books*
- *Existing validated instruments (eg SF-36 and WHO-DAS)*
- *Other*
- *Take into account work done by Euroreves*
- *Use of existing instruments: check relation with ICF as framework and purpose in chapter 2.*

### **Proposal**

- 1 discuss how we should use the UN guidelines (as a reference or as the recommended methodology)
- 2 workgroup 3 prepares a matrix with ICF dimensions/domains versus ICF checklist annex 9, recommended Eurostat items, OECD items, WHO-DAS items, SF-36 items in order to distinguish common elements
- 3 Emmanuelle Cambois recommends to Workgroup 3 how to take into account the Euroreves experiences in choosing relevant items
- 4 as a result there will be a list of recommended items which should be confronted with the results of other chapters of this paper.

## **6 How to assess needs and create involvement of**

*by Carlotta Besozzi for A and Don Lollar for B*

*This part should include a proposal how to organize the involvement of*

*A persons with disability (in the work of this working group and in surveys in the field (see also paper prepared by Gerry Hendershot and Kristin Mulhorn)*

*B and key policy decision makers.*

### **6A How to assess needs and create involvement of people with disabilities (in this working group and surveys)**

There are different levels in the involvement of people with disabilities. The first is political and has to do with the recognition, enshrined in the United Nations Standard rules on equalisation of opportunities for people with disabilities and reinstated in the draft UN convention on the rights of people with disabilities, that nothing about disabled people should be decided without disabled people (rule 18). Representatives of organisations of disabled people should be fully involved in all phases of decisions on disability measurement and in particular in the purpose for such measures..

For the disability community it is critical that research must be focused on the social model of disability, whereby disability is understood as a social construct, not necessarily a consequence of impairment. Also it is important to realize that an impairment based perception as historical may change and has to change. As our extended measurement set will be based on the ICF model, disability must be understood as a multidimensional concept relating to individual situations, but also activities and areas of life in which they participate, as wells as the facilitating or incapacitating role of the environment on all these elements.

People with disabilities should be involved in the design, testing and assessment of measures. in order to capture in the most effective way data on people with disabilities, it is critical to involve those to whom the measure is targeted to. Only people with disabilities themselves have the necessary experience to analyse the level of equal opportunities or identify obstacles to their participation, the objectives at the core of our measurement set.

False assumption and wrong understanding in the development of a questionnaire can end in misleading results. Content is never neutral.

People with disabilities should be considered as experts in their own right and involved on an equal basis.

It is important to build a structured and constructive dialogue between researchers and statisticians and representatives of organisations of people with disabilities in order to achieve mutual understanding.

An effort is needed on both sides to reach understanding of the mechanisms and limitations of measurement, but also on separating technical and content issues.

Positive experiences of such dialogue are documented in the presentation by Gerry Hendershot and Kristin Mulhorn, which compares the methodology used in 6 countries<sup>1</sup>, and in a report by Nolan, Watson, Williams and Gorby in designing and piloting an Irish disability research instrument based on WHO ICF<sup>2</sup>.

Both studies highlight the need to make such dialogue accessible, by providing for instance different formats of documents or ensuring accessibility of meeting rooms. Such measures should be also taken into account in the design of questions. Also in this respect the contribution of disability experts will prove critical.

One of key challenges is to encompass the diversity of people with disabilities in the questions asked, by going beyond physical disabilities. Also it is critical to fill the gap between the perception of the health and social professionals and the experience of people with disabilities themselves on questions such as severity of disabilities, health assessments, etc. (e.g. a blind born person would not consider his/herself as severely disabled..., or the confusion in certain definitions: mental instead of learning disabilities)

Disability representatives should be able to comment both on content and format of the questions.

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<sup>1</sup> Australia, Canada, France, the Netherlands, South Africa, and United States.

<sup>2</sup> Hendershot-Mulhorn, Assessing recommendations for increasing rate of response by persons with disabilities. Comparison across six national surveys and various authors, Designing and Piloting an Irish Research Instrument based on WHO ICF, National Disability Authority, Ireland.

Both studies previously highlighted underline the need to develop questions related to participation , as well as on environment in all main areas of life. This is consistent with the ICF, to which the disability movement has actively contributed.

There is also a need to improve the negative approaches to disability in the ways questions are formulated.

In the screening phase it is vital that the purpose of measurement is well explained to respondents and a positive approach to disability is highlighted. It is important to remember that disability is a stigmatizing concept in most cultures, and that respondents because of negative experiences might be also negatively biased towards social or health researchers.

We also recommend the involvement of disability organizations from different groups in the testing of sample questions. Also shortcomings should be reassessed with disability organisations and a second test should be made.

The accessibility of questions is a key issue. not only they should be made available in different formats and there should be the possibility of sign language interpretation for those who need this, but the questions should be also translated in easy to understand language for people with learning disabilities. There are organisations of people with disabilities that have the necessary expertise for this.

Once the questions are finalised we also recommend the use of interviewers with disabilities, as well as disability awareness training for all other staff involved.

## **Proposal**

The principle of consultation and dialogue with representative organisations of disabled people is among the key principles of Governance adopted by the Washington City Group at its last meeting in Brussels. Such recommendations should be translated in its concrete work towards the preparation of an Internationally comparable disability measure and in the derived national work.

- Members of the WG have a critical role in their country in the development of a fruitful dialogue between statisticians and researchers and the disability community at national level.

- Members of WG should be encouraged to establish contacts with representative national umbrella organisations of disabled people in view of the preparation of their position for the Washington City Group.
- National disability organisations should be involved in the implementation of the general measurement and extended sets at national level:
  - in the preparation of a sound translation into national context by ensuring a positive approach to disability
  - in ensuring the accessibility of the questionnaire (limiting therefore proxy responses) and
  - in testing.
- The training of interviewers should include a disability awareness training prepared with the participation of people with disabilities. Statistical offices and research bodies should be encouraged to recruit people with disabilities as interviewers.

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## **6B How to assess needs and create involvement of key policy decision makers**

### **Principles**

Several principles underlie this section. First, the explicit relationship at work in this exercise is that between information and decision making. That is, one assumes that the more relevant and comprehensive the information, the better the opportunity to understand a group of people. Second, there is the premise that if information and understanding have occurred, pertinent policies and actions can emerge that will positively influence people's lives. The third premise underlying this section is that the UN Standard Rules should provide the common reference for validating the need for extended disability measurement across countries.

### **Assessing needs of key policy decision makers**

We begin with the assumption that key policy makers may include elected officials, government staff, and disability advocates—regardless of country. The needs of these groups will usually differ. In addition, there are substantial differences in the needs of decision makers in developing and developed countries. Officials in developing countries will suggest that extended data on disability is irrelevant in view of the massive social problems confronting the general population. More comprehensive data on the characteristics or conditions of those citizens with disabilities will only detract from the larger issues of poverty, poor health, and unemployment among the population. Their needs focus on the economic resources to raise the standards for the total population, arguing that this will also help those with disabilities—without any specific data.

The fundamental influences contributing to decisions for elected officials are economic balanced by concern for the welfare of those who are in need of services. Policy makers must be clear that any data, but particularly expanded data for a subpopulation, will contribute to positive outcomes for their constituents, and be economically feasible.

Government officials responsible for data and programs addressing disability issues are often at odds, with statistical agencies being influenced by the relative strength of agencies competing to insert survey questions, the cost of additional questions, the space needed for questions, and the potential economic impact on government agencies. Governmental program officials, on the other hand, might be motivated to better understand the needs of those participating in or assisted by disability-related programs. This data would help them initiate or revise programs or policies related to the programs.

Advocates are usually focused on the unmet needs of people with disabilities in their country. The more relevant data available to describe this group, along with data comparing people with disabilities to the broader population, allows any disparities to be revealed. Advocates can justify expanded data collection, even in the face of increased costs, by arguing that increased participation, for example in work settings, will defray increased survey costs. In addition, they may suggest that this data collection, even if it is costly, is a matter of human rights--trumping economics with rights.

### **Creating involvement of key policy decision makers**

Involvement of key policy decision makers in the process of inclusion of extended disability survey sets rests on political and interpersonal skill. Key policy makers usually who are elected officials must be persuaded that extended disability data will benefit them and their constituents. Cultivating their involvement in the political/scientific process of including expanded disability questions will require building relationships. This process is most effectively implemented by members of the disability community. Officials, whether elected or not, are often influenced by personal interactions with those affected by the data or policies or programs. While there is always a danger that conflicting agendas will be highlighted, it is clear that people in any minority group are the best advocates for their own cause—in this case, more and better data to affect policy and programs.

A second strategy, however, should supplement this approach. Government officials who have an understanding of disability issues should also be involved in building a professional/scientific/policy case for extended question sets. This process is often laborious and painfully slow, but is required if internal credibility for inclusion of questions is to be built.

Disability advocates must be convinced that spending energy to get more questions so that more data is generated is worth their effort. Too often, advocates see data that do not match their experience or that they do not believe accurately represents the condition or characteristics of people with disabilities in their country. It often requires identifying individuals within the disability community who can see the importance of relevant data and are willing to put their influence in that direction.

The bottom line is that a coalition of government officials, researchers, and advocates must develop idiosyncratic strategies in the light of their circumstances. The elements of strategy must include the set of questions (prioritized according to importance in each country), partners, methods of getting questions vetted and by whom, and funding mechanisms where

necessary. Inclusion of extended disability measurement sets is usually not easy and requires acceptance of the often long-term work needed for the efforts to come to fruition.

### **Proposal**

- 1 "Given the diverse policymakers' needs and approaches, is there a role for the WG? The WG, under the auspices of the UN, and with concurrence from WHO, can influence national policy makers. UN/WHO support alone provides credibility for some. Beyond organizational support, the case for inclusion of extended disability sets, beyond the basic set, must be made on substantive grounds, including economic, programmatic, and human rights data.
- 2 A "white paper" specifically targeted to policy makers from the WG should include available current data on disability prevalence, the shortcomings and implications of the paucity of appropriate extended data for disability and rehabilitation/education/social welfare uses as well as adherence to the UN Standard Rules.
- 3 The WG, formally or informally, could set up a mechanism by which WG members could act as consultants for each other as deliberations begin in each country around extended sets. The substantive and emotional support for what is usually a protracted time period would be welcomed by each member, realizing that support is available. The basic set will often be difficult to negotiate--extended sets will be even more difficult.
- 4 Finally, the WG will need to share their experiences real-time with one another so that members can learn from one another how best to implement these extended sets. "

## 7 Methodological issues

*This should include issues such as:*

- a full population coverage (problems: children sample problem and special instruments, institutionalized population how to interview, homeless people how to find them, selective non response eg by blindness, deafness, mental problems, etc); this issue will be covered by Howard Meltzer session during the WG4 meeting*
- b cultural appropriateness/sensitivity issues*
- c other issues such as: proxi interviews, scoring system, recommended grouping and tables*

### **Proposal**

No action at this moment.

Wait for results of Bangkok meeting.

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## 8 Testing

*This should include issues such as:*

- *initial testing (cognitive)*
- *larger scale piloting*
- *feed back of testing results into redesign and possibly further testing*

### **Proposal**

No action for this moment.

Wait for developments during next meeting

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## 9 Implementation issues

*This part should include issues such as:*

- *Validation of the sets(s)*
- *Translation*
- *Training for uses, coding, analyzing, etc*
- *Educational/explanatory material*
- *How to reach those who should apply the sets(s) and to get them interested*
- *See also papers by Howard Meltzer regarding quality assurance*
- *Comparability of data to be treated by WHO (Nenad/Somnath); is there a need for any post harmonization if the work aims at pre-harmonization (reference instruments!)*

### **Proposal**

No action for this moment.

Wait for developments during next meeting.

## **10 Next steps**

### **Proposal**

To be decided in the WG4 meeting after discussion of the position paper

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**Annexes**

*(separately mailed)*

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