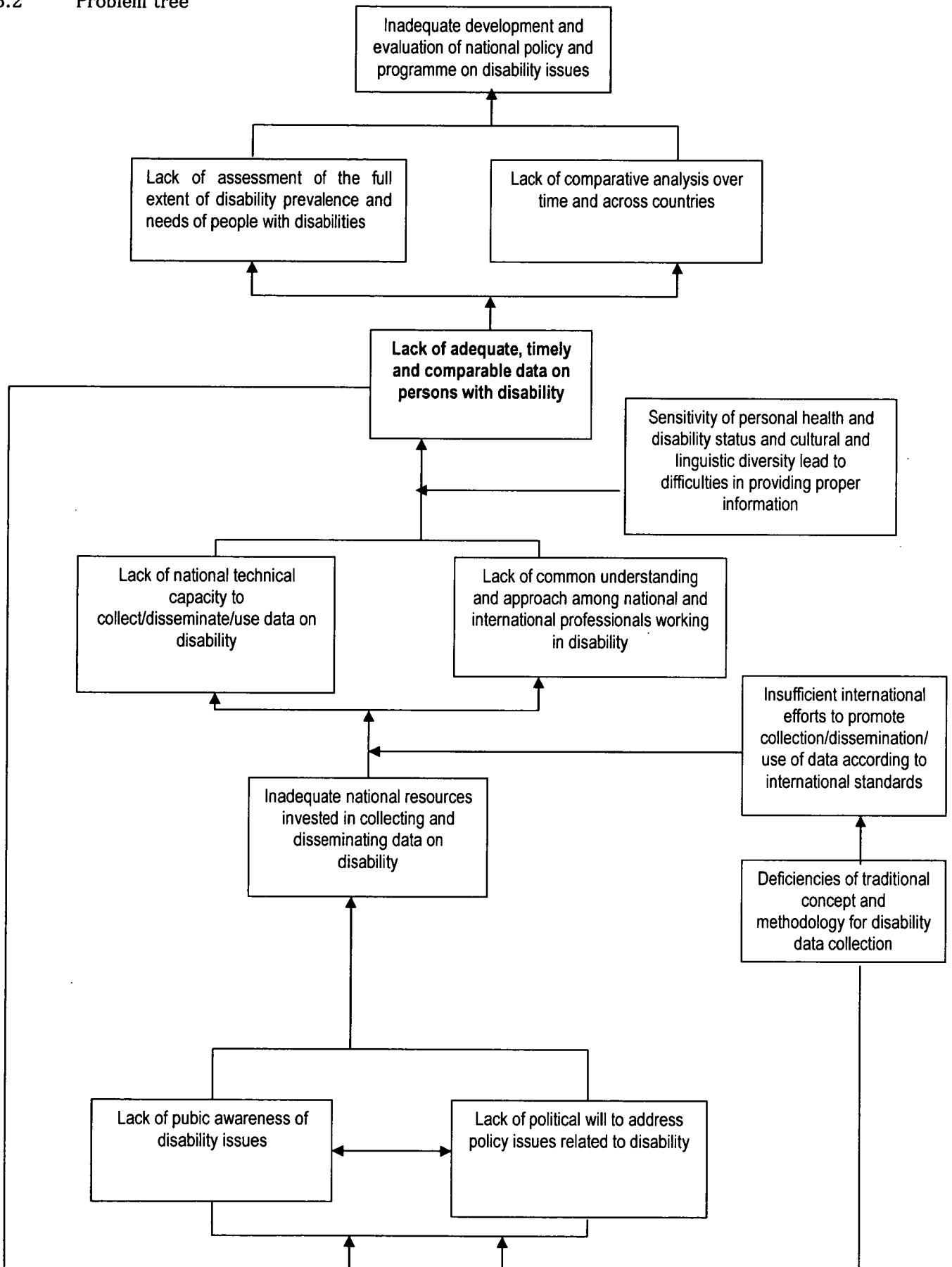


progress towards national and the BMF targets. Benefiting from international standards to be developed under the project and increased understanding of the benefit of ICF-based data, countries will be more willing to continue disability data collection and dissemination on a sustainable basis after the completion of the project.

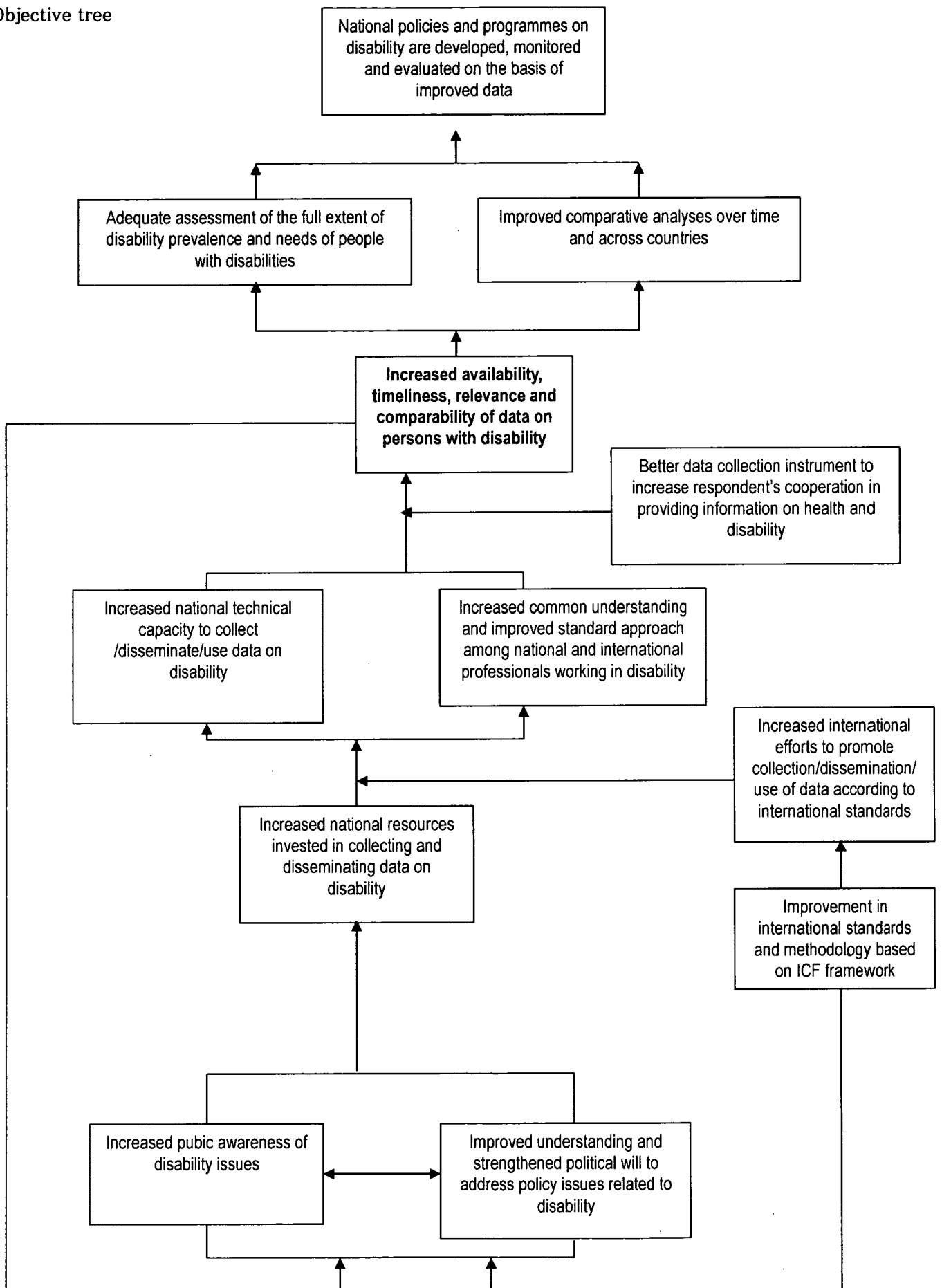
Non-project participating countries in this region will also benefit from the project implementation. It is expected that the project will act as a catalyser for the adoption of the ICF-based approach for disability data collection in more countries, thereby contributing to the “snowball” effect on the improvement of disability statistics in the region. Not only the web-based knowledge management tool will be useful to all countries, but the regional network of national experts from participating countries, including women and persons with disability, will be established through this project to facilitate knowledge sharing and technical cooperation among countries in the region.

This project will rely on existing regional cooperation and partnership with leading partner agencies, including the WHO, the Washington Group, SIAP, DESA and some NSOs (such as Australia and the Philippines), and new partnership with the Budapest Initiative on Measurement of Health Status. While these partners will provide critical technical guidance and inputs into the project design and implementation, the project outputs will, in turn, provide feedback into the continuing process of international methodological development in the field. The project objective and activities are consistent with the on-going efforts by the partner agencies, so a continuity or expansion of the project activities beyond the current phase is highly probably.

3.2 Problem tree



Objective tree



4. OBJECTIVES, EXPECTED ACCOMPLISHMENTS AND STRATEGY

4.1 Overall objective

Target countries have integrated ICF-based data collection on disability into their regular national statistical systems, thereby improving availability, quality and comparability of disability statistics to support policy formulation and promote implementation of the BMF.

4.2 Expected accomplishments

The implementation of the project is expected to result in:

1. Improved understanding of the ICF approach to disability measurement by NSOs, health professionals and policy makers in the region.
2. Increased national technical capacity for collecting disability statistics in accordance with ICF standards and regional guidelines for national censuses and surveys, which also reflect gender concerns.
3. Increased knowledge-sharing and joint activities among ESCAP members in the field of disability statistics.

4.3 Activities

The project will achieve its expected accomplishments through an integrated approach by combining development of standard measurement tools for disability data, collection, pilot studies and analyses, with in-country advocacy workshops to raise awareness and commitment among a wider range of stakeholders, targeted training of statistical experts and health professionals to improve their technical capacity, country advisory services to support national data collection efforts, and the promotion of country-to-country cooperation and knowledge sharing. These activities are designed to address the needs of countries in the region, expressed explicitly at regional workshops or other forums organized under the previous ESCAP/WHO project. The central effort of the current project will, to the extent possible, focus on developing standard measurement for collecting disability data through surveys, including post-census surveys.

While the specific design and concrete implementation plan will be established during the proposed Project Preparatory Phase, the proposed activities are as follows:

Under the expected accomplishment (EA) 1

Advocacy for ICF approach among a wide range of stakeholders

A1.1 Conduct six (6) in-country advocacy workshops in project countries, i.e., those who will conduct pilot test of proposed survey question set (see activities under EA 2), on the ICF and its implementation for disability data collection and analysis. These workshops will include a broad range of stakeholders, national statisticians, health professionals, policy makers and other relevant data user groups. These workshops may be

organized in connection with advisory missions by project consultants in preparation of pilot tests (see activities on pilot tests and country advisory services) and/or in-country training requested by countries.

Promoting disability data collection through the upcoming censuses

A1.2 Organize a small-scale regional workshop on the current UN global recommendations on census-based disability data collection and dissemination. This activity will help promote the integration of disability in the upcoming 2010 round of census, which provides a critical opportunity to obtain better data on disability prevalence and a necessary basis for conducting disability surveys, including post-census surveys. Participating countries will be those who plan to include or are considering to include disability topic in the next census, identified through an upcoming survey of national census plans, to be conducted by ESCAP Statistics Division under the Regional Census Programme.

Developing knowledge management tools

A1.3 Develop and disseminate an interactive CD-ROM version of the ESCAP/WHO Disability Statistics Training Manual produced under the earlier project. The CD-ROM version will facilitate training and will be accessible for persons with disabilities.

A1.4 Develop a web-based knowledge management tool to promote the understanding and implementation of ICF-based disability measurement development, and data collection and dissemination. This web-based tool will compliment the training manual with additional instructive references, examples of best practices, and other project background materials. It may also include on-line discussions on specific technical issues among regional and international experts to facilitate knowledge sharing.

Under the expected accomplishment (EA) 2

Developing survey-based standard measurement

A2.1 Develop an extended set of questions for survey-based data collection on disability, to be tested and refined through country pilot studies in the region to formulate an empirical basis for establishing international recommendations on standard survey instrument for disability data collections. The objective is to develop survey-based standard instruments that offer practical solution to facilitate national efforts to include disability data collection in regular statistical data collection activities. The development of the question set will be integrated into the work plan of the Washington Group as approved at this year's UN Statistical Commission.

A2.2 Develop standard protocols for country pilot tests on the proposed survey-based question set (including technical guidelines for survey preparations and sampling requirements) and subsequent data analyses plan.

A2.3 Organize one pre-pilot test regional workshop with participants from the project countries to establish a collective understanding of the objectives and guidelines for pilot testing. The workshop will provide an opportunity for project countries to discuss with ESCAP and other project partners relevant technical and logistic issues – either common or country-specific – to ensure successful implementation of country pilot studies.

A2.4 Conduct pilot tests of the proposed survey-based extended set of questions on disability in 6 ESCAP member countries, including at least one Central Asian country and one Pacific Island country. Pilot tests are to be designed to ensure that, to the extent possible, the relationship between gender and disability is covered.

A2.5 Produce joint analyses by key project partners of pilot test results to refine the proposed

survey-based extended question set and formulate a basis for establishing international recommendations. The joint analysis will be conducted in cooperation with project countries to make it an opportunity for further national technical capacity building on disability data collection and analyses. The project partners will seek to publish the results from the joint analyses in a leading international journal or at relevant open forums to inform national and international discussions on improving disability measurement.

A2.6 Conduct one post-pilot study workshop to review pilot test results and refine the proposed survey-based standard instrument for disability data collection. The workshop will include project countries and other interested countries in the region, thereby extending the opportunity of knowledge-sharing and technical capacity building among a wider range of countries in the region.

Under the expected accomplishment (EA) 3

Establishing a regional network of experts

A3.1 Establish a regional network of national experts on ICF-based approach to disability data collection and dissemination to facilitate country-to-country technical cooperation. This pool of experts, who were trained either under the previous ESCAP/WHO project or through the various activities of the current project, could serve as the resource person for country advisory services or other country capacity building activities on disability statistics in the region.

Providing country advisory service

A3.2 Advisory missions to provide assistance to countries with data collection design in accordance with ICF standards and conduct pilot study data analysis; where possible, advisory missions will also be conducted on occasions of in-country training workshops for a wide range of stakeholders to complement SIAP sub-regional training courses. Advisory missions are determined by needs as specifically expressed by countries and will particularly target those with upcoming population censuses or disability-related surveys. Advisors who conduct missions should have sufficient knowledge of relevant gender issues.

4.4 Strategy for project implementation

The over strategy of the project will build upon lessons learned from the previous ESCAP/WHO 2004-06 project on "Improvement of Disability Statistics and Measurement in Support of the BMF" led by the Statistics Division of ESCAP. Due to the strong policy relevance for the region, the previous project made a strong and positive impression on the process of developing member countries' national statistical systems through close collaboration with ESCAP's internal partner of Emerging Social Issues Division. The project was implemented successfully through an integrated approach, combining pilot studies and regional recommendations with advocacy, training, and country advisory services. It was also clearly shown that close collaboration on methodological issues with international partners was an imperative component to ESCAP's overall strategy. This international partnerships need to be expanded and strengthened.

The project implementation will be guided by the following specific strategies.

Focus on developing survey-based standard measurement. While the project is designed to pursue a combination of activities, ranging from advocacy to knowledge management, based on the country needs in the region, its core resources will be devoted to the development of standard measurement for collection of disability data through surveys. This strategy reflects the current focus of the ongoing global initiatives and extends naturally from the emphasis of the 2004-06 ESCAP/WHO project on census-based questions. The extended set of survey-based question will be based on the ongoing global initiatives, including the question sets tested in the previous ESCAP/WHO project and the short census question set promoted by the Washington Group. In

accordance with the ICF, the extended set should capture disability as a universal and multi-dimensional experience by eliciting data about functioning levels in multiple life areas. This will allow more adequate identification of the prevalence and needs of people with disabilities.

Rely on close partnership. The project activities will be designed and implemented through close partnership between ESCAP and other international and national partners, including DESA, the Washington Group, WHO, the Budapest Initiative on Measurement of Health Status and ECE and selected national statistical offices in the region, and with ESCAP internal partners, mainly the Emerging Social Issues Division (ESID) and SIAP⁴. Through the earlier ESCAP/WHO disability project, ESCAP has established strong cooperation with many of these partners. Our common vision and complementary technical capacity provides a solid basis for the successful implementation of the current project.

From project preparatory phase to active implementation. The initial five months of the project will be devoted to a Project Preparatory Phase, during which a detailed project design and implementation plan will be mapped out with the assistance of a wider group of leading experts. The preparatory phase is essential for key international partners and national experts to jointly develop a proper set of standard instrument (and related technical guidelines) to be pilot tested and refined through the project, and to collaborate effectively on the other main project activities.

From target group to “spill-over” effect. The target group of the project are project countries undertaking pilot test of the proposed survey-based standard instrument, selected on the basis of expressed country interest and technical “readiness.” These countries will benefit from the full range of proposed project activities, including in-country advocacy, technical support through advisory services and regional workshops for project planning and knowledge sharing. However, the project will reach wider influence through three main mechanisms: (1) the participation of countries beyond the project countries in regional workshops, such as the workshop on census data collection and the post-pilot study workshop; (2) access to the web-based knowledge management tool and interactive training manual; and (3) the potential use of the regional network of national experts, trained through the project, for country-to-country technical cooperation. In identifying project countries and other participating countries, special attention will be given to ESCAP priority countries, including those in the Pacific region and from Central Asia.

Promote country-to-country technical cooperation. A regional network of national experts on ICF-based disability data collection – trained through the earlier ESCAP/WHO disability project and the current project – will be established through this project. Through this network of national experts, the project aims to promote country-to-country technical corporations, especially South-South corporations, to expand the knowledge base in the region and improve national technical capacity for ICF-based disability data collection through efficient use of local expertise.

⁴ The ICF-based training activities in the region (sub-regional or in-country) will be managed and implemented by SIAP, therefore not included in this project.

4.5 Relationship with other projects

The current project is an integral part of ESCAP's wider effort to promote the implementation of the Biwako Millennium Framework for Action for the Decade of Disabled Persons (2003–2012). Its precedent, the 2004–06 joint ESCAP/WHO disability project, was born directly out of the call of BMF, and itself is closely linked to the Japan-funded on-going project "Towards the Regional Mid-term Review of the Implementation of the Biwako Millennium Framework for Action for the Decade of Disabled Persons (2003–2012)," led by the ESID. It will continue to be guided by the policy framework of the ESID project and aim to directly support the ESID project through both close collaboration on the preparation for regional meetings on monitoring and implementation of the BMF and the expected impact of the project on improving disability statistics in the region.

There will also be further collaboration with ECE in its efforts to strengthening national statistical capacity in producing health statistics, including disability statistics, among Central Asian countries. Currently, ECE is implementing a Development Account project on strengthening statistical capacity among member countries of the UN Special Programme for the Economies of Central Asia (SPECA) to monitor demographic, social and economic progress toward the implementation of the Millennium Declaration. Beneficiary countries are Azerbaijan, Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, Uzbekistan, and partially Afghanistan. The project focuses on three statistical areas – population and social conditions, health status of the population and economic development. In this connection, ECE has already collaborated with the Statistics Division of ESCAP in conducting a training workshop on disability statistics for SPECA countries in December 2006. At this workshop it was agreed that, based on expressed country interest, this current project would include as least one SPECA country in the pilot study and, to the extent possible, include other countries in the planned regional workshops. Another workshop on health statistics is scheduled to take place in November 2007 which will include follow-up discussions on disability statistics and provide an opportunity to identify a project country from the region for this project. Moreover, ECE Statistics Division has strong experience in disability measurement research and lends itself nicely as one of the key partners for the current project.

The Washington Group, in its current work plan approved by the UN Statistical Commission in March this year, clearly identified ESCAP as a partner in joint research and work on developing survey-based standard instrument. Its shift of focus from census to survey-based measurement development and plan to increase involvement in training and dissemination activities are consistent with this proposed project. As a project partner for the earlier ESCAP/WHO project, ESCAP and the Washington Group have developed stronger collaboration over time, and are both committed to work together to promote the development of international standards through the current project.

5. MONITORING AND EVALUATION

The project will adopt the following complementary measures for monitoring progress and evaluating impact.

Monitoring

While ESCAP will be the lead agency in managing the project implementation, a small Steering Committee overseeing the overall project design and implementation would be set up. The Committee would include representatives from DESA, WHO, the Washington Group, ECE, the Budapest Initiative and a selected number of NSO experts. In addition to occasional face-to-face meetings, the Committee will primarily

communicate through email or teleconference for periodic project updates, and discussions and decisions on issues related to project operation and possible adjustments.

ESCAP will prepare regular updates and submit to the Steering Committee for review and discussion. These updates will draw the attention of the Steering Committee to any emerging issues to be addressed and/or the need for project adjustments, and request decisions from the Committee for subsequent actions.

Evaluation

During the Project Preparatory Phase, a more detailed evaluation plan will be developed. Currently we propose that the expected achievements of the project be verified with simple indicators, as described in the Simplified Logical Framework (Annex I). According to the type of project activity, specific information will be collected for project evaluation. For example,

- Workshop evaluation questionnaires will be used for assessing the impact of the advocacy/training workshops. Pre-workshop and post-workshop surveys will be carried out, using the questionnaire with specific questions on the contents of the workshops in order to evaluate whether a significant increase in knowledge of participants achieved or not.
- Survey of national statistical activities and publications through questionnaires or review of national statistical reports will be carried out to determine the impact of the activities in pilot studies, advocacy and advisory services. Comparison analysis between project countries and non-project countries will be carried out in this regard.
- Country reports of participating pilot countries will be used to assess the quality of the specific project activity.
- Website access log will be used to evaluate the usefulness and extent of outreach of the knowledge management tool.

An overall substantive project evaluation is set to take place at the end of the project period.

6. EXTERNAL FACTORS

The project is expected to achieve its objectives on the assumption that national governments, institutions and local authorities give sufficient priority to disability issues and are willing to provide the necessary support for statistical activities on disability.

It is also assumed that (i) the interest of targeted beneficiaries in issues related to disability is sustained; (2) regional and international technical support for country project activities remains adequate; (3) project activities are in line with level of statistical development and national statistical priorities; 4) project participating countries are committed to carry out designed activities; 5) governments and NSOs are willing to share information and country experiences with other countries and regional and international partners; and 6) appropriate national statistical staff are nominated for participating in project activities and retained in the system to implement planned project activities and to provide sustainable technical capacity in national statistical offices.

7. IMPLEMENTATION ARRANGEMENTS

The Statistics Division of ESCAP will be the lead agency responsible for the management of the project, overseen by a Steering Committee comprised of key project partners and national experts. ESID will be the internal collaborating partner, providing policy guidance for the project and updates on the data needs related to the BMF. It will also be invited to provide direct inputs in the design of advocacy workshops and in the relevant regional workshops proposed under this project to address disability issues from social policy perspective.

Other internal partners include SIAP, who is responsible for developing and implementing relevant sub-regional and national training programme on disability statistics.

The Statistics Division of ESCAP will implement the project in close partnership and collaboration with external partners, including DESA (Statistics Divisions and Division for Social Policy and Development), WHO, the Washington Group, ECE, the Budapest Initiative and selected NSOs on designing and implementing the whole range of project activities. Experts from these partner agencies will provide technical inputs and serve as resource persons.

Project assistant/consultants will be hired to provide specific support for the implementation of various project activities, including: (1) designing survey-based standard question set; (2) designing pilot study protocols; (3) conducting pilot studies in project countries; (4) developing pilot study analysis plans and carrying out joint research; (5) designing and conducting in-country advocacy workshops; (6) assisting with regional workshops and follow-up activities; (7) providing advisory services to countries; (8) creating an interactive CD-ROM version of the Disability Statistics Training Manual, and (9) assisting in developing the web-based knowledge management tool.

Other potential partners and resources include international NGOs, such as the Handicap-International, who is designing and implementing disability data collection in selected countries (e.g., Afghanistan and Cambodia) in this region.

ECE has long involvement in the measurement work on disability and is ESCAP's partner in technical cooperation projects for SPECA countries. This project provides an opportunity for further collaboration with ECE to implement the project activities in SPECA countries. Moreover, there will also be possible collaboration with the Secretariat of the Pacific Community (SPC) and ESCAP's Pacific Operation Centre in Suva, Fiji on project implementation in the Pacific region.

ANNEX 1: SIMPLIFIED LOGICAL FRAMEWORK

Intervention Logic	Indicators	Source of verification	Risks/Assumptions
<p>Objective: National disability policies and programmes, following the BMF and other international development goals, are developed, implemented and monitored on the basis of improved disability statistics in the Asian and Pacific Region.</p>			
<p>Expected Accomplishment (EA)1 Improved understanding of the ICF approach to disability measurement by NSOs, health professionals and policy makers in the region.</p>	<p>1) Increased number of participating NSOs using ICF standards and regional guidelines in national censuses and surveys, comparing to the non-participating countries.</p> <p>2) At least 80% of workshop participants who indicate that their knowledge and understanding have increased, through pre-workshop and post-workshop surveys, using the questionnaire with specific questions on the contents of the workshops.</p>	<p>1) Workshop and training records.</p> <p>2) Records of pre and post workshop questionnaires.</p> <p>3) NSOs' work plan and programme activities.</p> <p>4) CD-ROM Users' surveys.</p> <p>5) Website access logs.</p>	<p>1) Sustained interest of targeted beneficiaries in issues related to disability.</p> <p>2) Regional and international technical support for country project activities remains adequate.</p> <p>3) Project participating countries are committed to carry out designed activities.</p> <p>4) Governments and NSOs are willing to share information and country experiences with other countries and regional and international partners.</p> <p>5) Appropriate national statistical staff are nominated for participating in project activities and retained in the system to implement planned project activities and to provide sustainable technical capacity in national statistical offices.</p>
<p>Main Activities contributing to EA1 <i>Advocacy for ICF approach among a wider range of stakeholders</i></p> <ul style="list-style-type: none"> Six in-country workshops on the ICF and its implementation for disability data collection and analysis. <p><i>Promoting disability data collection through the upcoming census</i></p> <ul style="list-style-type: none"> A small-scale regional workshop on census-based disability data collection. <p><i>Developing knowledge management tools</i></p> <ul style="list-style-type: none"> Develop and distribute an interactive CD-ROM version of the ESCAP/WHO Disability Statistics Training Manual, which will facilitate training and self-learning; Develop a website on disability measurement and statistics collection and analysis. 			
<p>Expected Accomplishment (EA) 2 Increased national technical capacity for collecting disability statistics in accordance with ICF standards and regional guidelines for national censuses and surveys, which also reflect gender concerns.</p>	<p>1) Increased number of NSOs providing disability indicators for policy making and analysis.</p> <p>2) Increased number of countries that are developing or improving national disability information systems (by planning for example disability-specific surveys) in line with international recommendations developed from this</p>	<p>1) Quality assessment of national disability data submitted to UN in 2007 and onwards</p> <p>2) Evaluation questionnaires administered during the workshops.</p> <p>3) Monitor national follow-up actions either through special survey or routine bilateral correspondence.</p>	<p>1) The interest of targeted beneficiaries in issues related to disability is sustained.</p> <p>2) Regional and international technical support for country project activities remains adequate.</p> <p>3) Project activities are in line with level of statistical development and national statistical priorities.</p> <p>4) Project participating countries are committed to carry out designed activities.</p>

Intervention Logic	Indicators	Source of verification	Risks/Assumptions
	project.	4) NSOs' work plan and programme activities. 5) Pilot study country report.	5) Governments and NSOs are willing to share information and country experiences with other countries and regional and international partners. 6) Appropriate national statistical staff are nominated for participating in project activities and retained in the system to implement planned project activities and to provide sustainable technical capacity in national statistical offices; selected country participants are: <ul style="list-style-type: none"> • Familiar with statistical data collection methods and sufficiently fluent in English; • Committed to working in disability area at least 2 years after the project expired at the end of 2009; • Given opportunity to follow all the training and workshop activities.
<p>Main Activities contributing to EA2</p> <p><i>Developing survey-based standard measurement:</i></p> <ul style="list-style-type: none"> • Developing an extended set of questions for survey-based collection on disability; • Developing standard protocols for country pilot tests and subsequent data analysis plan; • Pre-pilot study regional workshop with participants from the project countries; • Pilot testing of proposed survey-based extended set of questions in 6 ESCAP member countries; • Produce joint analyses by key project partners of pilot test results to refine the proposed survey-based extended question set and contribute to international recommendations; • Post-pilot study workshop to formulate international recommendations on instruments censuses and surveys. 			
<p>Expected Accomplishment (EA) 3</p> <p>Increased knowledge-sharing and joint activities among ESCAP members in the field of disability statistics.</p>	1) Increased number of South-South cooperation in developing or improving national disability information systems facilitated by this project. 2) Increased number of country-to-country exchanges of experience and cooperation efforts in the field of disability statistics and implementation of the ICF.	1) Monitor national follow-up actions either through special survey or routine bilateral correspondence. 2) Advisory mission reports. 3) NSOs' work plan and programme activities. 4) Evaluation questionnaires administered during the in-country workshops if possible.	1) The interest of targeted beneficiaries in issues related to disability is sustained. 2) Regional and international technical support for country project activities remains adequate. 3) Project activities are in line with level of statistical development and national statistical priorities. 4) Governments and NSOs are willing to share information and country experiences with other countries and regional and international partners. 5) Appropriate national statistical staff are nominated for participating in project activities and retained in the system to implement planned project activities and to provide sustainable technical capacity

Intervention Logic	Indicators	Source of verification	Risks/Assumptions
			<p>in national statistical offices; selected country participants are:</p> <ul style="list-style-type: none"> • Familiar with statistical data collection methods and sufficiently fluent in English; • Committed to working in disability area at least 2 years after the project expired at the end of 2009; • Given opportunity to follow all the training and workshop activities.
<p>Main Activities contributing to EA3</p> <p><i>Establishing a regional network of experts:</i></p> <ul style="list-style-type: none"> • Establish a regional network of national experts on ICF-based approach to disability data collection and dissemination to facilitate country-to-country technical cooperation. <p><i>Providing country advisory service:</i></p> <ul style="list-style-type: none"> • Advisory missions to provide assistance to countries with data collection design in accordance with ICF standards and conduct pilot study data analysis. 			

ANNEX 2: RESULT BASED WORK PLAN

Expected Accomplishment	Aspect of Project	Main Activities	2007	2008	2009
EA 1: Improved understanding of the ICF approach to disability measurement by NSOs, health professionals and policy makers in the region.	Country Workshops for Advocacy	A1.1 Conduct six in-country workshops on the ICF and its implementation for disability data collection and analysis.		X	X
		A1.2 Organize a small-scale regional workshop on census-based disability data collection.		X	
	Knowledge Management	A1.3 Develop and disseminate an interactive CD-ROM version of the ESCAP/WHO Disability Statistics Training Manual, which will facilitate training and self-learning.	X	X	
		A1.4 Develop a web-based knowledge management tool on disability measurement and analysis.	X	X	X
EA 2: Increased national technical capacity for collecting disability statistics in accordance with ICF standards and regional guidelines for national censuses and surveys, which also reflect gender concerns.	Development of survey-based standard measurement	A2.1 Develop an extended set of questions.	X	X	
		A2.2 Develop standard protocols for country pilot studies and subsequent data analysis plan.	X	X	
		A2.3 Organize a pre-pilot study regional workshop with participants from project countries.		X	
		A2.4 Conduct pilot tests of the proposed survey-based extended set of questions in 6 ESCAP member countries.		X	X
		A2.5 Carry out joint analyses of pilot test results.		X	X
		A2.6 Conduct a post-pilot study workshop to review pilot test results and refine the proposed survey-based question sets for disability.			X
EA 3: Increased knowledge-sharing and joint activities among ESCAP members in the field of disability statistics.	A Regional Network of Experts	A3.1 Establish a regional network of experts on ICF-based approach to disability data collection and dissemination.	X	X	X
	Country Advisory Services	A3.2 Advisory missions to provide assistance to countries with data collection design in accordance with ICF approach.	X	X	X

DRAFT PROPOSALS FOR EXTENDED SETS FOR DISCUSSION

Washington Group on Disability Statistics

Presentation to 7th WG meeting, Dublin, Ireland

19 – 21 September 2007

This document is drafted based on a series of iterative inputs received over the year since the 6th WG meeting in Kampala in October 2006. Two draft documents were sent to the whole working group on extended sets. The comments received are incorporated as far as possible with a clear indication where consensus has been reached. Where there is clearly no consensus the different positions are set out. The document will be discussed and decisions made by the WG participants in Dublin.

Some general principles for the extended sets

1. The anticipated outcome of the work of the extended workgroup is a set or sets of questions that are feasible and provide the best possible cross-country comparability.
2. All the set(s) should fulfill the purposes of equalization of opportunities and prevalence of disability.
3. The framework of reference for all sets is the ICF and these sets (or this set) should provide a holistic picture of disability and functioning in participating countries. In addition the terminology used should reflect the ICF use of various terms as follows:
 - Functioning and disability are broad umbrella terms referring to the overall experience and are not limited to body function or activity limitations.
 - Impairments of body function and structure
 - Activity limitations at level of the person's execution of activities
 - Participation restrictions at the level of the person + environment
 - Environmental barriers and facilitators
 - Personal factors
4. As far as possible existing sets that cover the desired scope of new question sets will be identified and critically reviewed before the decision to develop new question sets is taken.
5. This short set and extended sets should be congruent with each other in the way the questions are phrased as well as in the response options. There should also be coherence between the sets; i.e. where measures on the short set should reflect as far as possible measures on the extended sets.

A framework based on the ICF

The framework on which the extended sets are to be selected are as follows:

- Disability is defined in the ICF as an outcome of the interaction of a person with a health condition with the context in which that person lives. The components that make up this include the three levels of body function and structure, activity and participation all as outcomes of the interaction, with Environmental and Personal factors being the factors that interact with the person's health condition. Thus to fully understand disability (and its counterpart – functioning) these need to be all covered.
- The starting unit of measure will be activities and activity limitations with a definite inclusion of basic activities – there is general consensus on this and that there should at least be a set that takes this aspect into more detail.
- There is some push for the extended sets to include measures of more complex activities. However, there is no clear consensus on this. Some of the arguments presented against including more complex domains is that these become too culturally specific and hence difficult to compare across countries or contexts. (This is

discussed further below.) Arguments for including these more complex activities is that this provides a more comprehensive description of the experience of disability.⁵

- There is some but not general consensus that the domains of activity should be considered both with and without assistance, where assistance refers to both technical/technological as well as people/attendant assistance.
- Environment is essential to include as a component in the extended sets but there is no agreement on the way in which this should be done. The proposal on how to include Environment in the sets is discussed further below.

Purpose of the sets

The consensus seems to be that the extended sets should have the same purposes as for the short set – viz. equalization of opportunities and prevalence of disability.

The data collected for these two purposes is to be used both for individual country needs as well as for international reporting. Once the extended sets have been developed, a set of guidelines should be developed to assist countries in using the sets and the data generated in a meaningful manner.

Proposal for sets

There is general consensus that there will be more than one set of extended questions. There is, however, no clear consensus on the exact nature of these.

Below are two proposals on how the sets should be organized:

Proposal 1:

Two types of sets –

- One that focuses on functioning (in broad ICF sense – A and P) and environmental factors (E), and
- one that focuses on more personal factors as well as features of the difficulties experienced (e.g. duration, age of onset, frequency of occurrence and intensity). (Complementary questions to functioning.)

The extended sets are as follows using the nesting principle where the first set can be found in the second and so on:

- Three sets of questions that collect information on functioning that all meet the purposes of monitoring equalisation of opportunities as well as prevalence of difficulties/disability:
 - a) A parsimonious set of questions that include the domains and related questions that explain at least 80% of the variation in population functioning and with no explicit measurement of environmental factors⁶. [What should be the optimum percentage to indicate here?]
 - b) A (one) more detailed set that includes domains not covered in the parsimonious set and that provides information for all types of difficulties (wide coverage of ICF A/P classification) to provide as full a coverage of functioning and disability. Questions on environmental factors would include micro level questions relating to technical and personal assistance with the possibility of a couple of more general questions on the broader environment.
 - c) A detailed set as for b) with a detailed set of Environment questions that cover the micro, meso and macro⁷ levels of environment.

⁵ There is disagreement in relation to this basic vs complex distinction, and the issues remains, again in relation to this point, on how to define Activity and Participation.

⁶ Although questions on Environment would not be explicitly included there might still be information on some basic usage of assistive devices such as glasses or hearing aids as within the short set.

⁷ Micro environment is made up technical and personal assistance that the person uses and that go with the person wherever they go (e.g. wheelchair, eye glasses, personal attendant and the attitudes of people in the

- An additional set of questions should be developed to cover personal factors such as age of onset and cause of the difficulty, duration of the difficulty, frequency and intensity of the difficulty, impact of pain, level of distress, etc. These questions will be asked in relation to the activity limitation (e.g. When did your difficulties start?).

Question: should the features of the duration, frequency, etc. be asked together with personal factors or together with the A/P in set b) above?

See Appendix A for a more detailed description of these proposed sets.

Proposal 2: (not so much specific sets as suggestions for sets)

- The basic parsimonious is the short set. But we had agreed that there were additional domains that should be included but for which we didn't have time or space on the short set. The discussion is then whether we want an extended set that includes additional domains and how to choose them.⁸ We are summarizing functioning over core domains and while we need a way to determine which domains to include, there are conceptual as well as statistical (what explains the most variance on some other measure) issues to consider now that we don't have the time/space constraints of a Census. While the main objective for the short set was to create a measure of disability status, for the extended sets we might also want to be able to provide domain by domain information.
- There are two questions--do we need to add domains and do we need to add questions within the domains to better meet the purpose?
- To evaluate equalization of opportunity, our approach has been to create a disability status variable and then see whether participation/inclusion rates are the same for each group. This is the sense that the measure is a demographic.
- A further question is whether we want to develop an extended set that allows us to understand how the 'demographic' affects inclusion--that is we would be further unpacking the interaction. This would be adding or expanding on the original purpose rather than adopting a new purpose. Within the 'disabled' group, we could try to distinguish those whose functioning levels change due to the use of assistive devices as opposed to those who use devices but still have difficulties as opposed to those who do not use devices. We could then determine how the use of devices affects participation/inclusion in much the same way that we have been evaluating inclusion. Adding questions on assistance within the domains covered creates a new set by expanding on the questions in a smaller set (either the current short set or an expanded set).
- Another decision point is whether to add additional questions on the nature of the functioning (e.g., onset, freq, duration, etc) within the domains covered. This would provide a richer description of functioning in that domain and could assist in explaining how the interaction plays out.
- A new purpose (or maybe a further exploration of differential participation/inclusion) could be an assessment of the environment. We could consider creating a new, totally separate set that obtains information on the larger environment. These questions wouldn't be domain specific. Environment could be very broadly defined or more limited.
- Another new purpose could be to address the fulfillment of societal roles. This is where we start worrying a lot about cross national comparability. Although the requirement for comparability must be met for each stage, it is probably most problematic for the more complex the task.

Some outstanding issues for discussion

- What is meant by cross country comparability and cultural factors that make this difficult?
Let's consider some examples:

person's immediate environment). The Meso environment is the broader environment that affects not only the person (e.g. state of the roads and paths in a community, service provision at local level). The Macro environment is that which affects a whole country, such as policies and legislation, general societal attitudes and practices, and so on.

⁸ To what extent do or don't the WHO/UNESCAP and World Health Survey (WHS) question sets meet this criteria?

- We are reasonably sure that when we ask about difficulties walking that respondents in all countries have a similar sense of what walking means. We can be less sure of how they average out their walking ability across the environments they usually walk in to give a final response to the question ‘How much difficulty do you have in walking?’. So in the end are we measuring the same ‘walking’ across countries?
- When we want to know the prevalence of activity limitations in the domain of personal interactions, we are much less sure of whether we can get cross comparable measures. But this is not necessarily the case. A country will collect information on difficulties people have in interpersonal interactions and relationships (e.g. difficulty making and maintaining friends, dealing with conflict, getting on with family, friends, strangers, etc.). The responses will have been mediated by what is the cultural norm in that country. This norm will differ across countries and can these differences can be studied in their own right. So in the end we measure prevalence of difficulty in relation to a cultural norm that is country specific, but we can compare the generic level of difficulty across countries. So the generic domain of interpersonal interactions and relationships is what is being compared and not the cultural specific reference.

This difference between generic domains for cross country comparability and cultural specific references in how people respond is a framework to consider in ensuring that we do not limit ourselves to only asking about basic domains of activities and thus provide a limited picture of disability. (Cf Appendix D for further discussion on these issues from the July document sent to the Extended sets workgroup)

- What is meant by equalization of opportunities and how do the extended sets ensure this purpose is met?
- Wording of questions
There are different ways in which to word the questions: How much difficulty... vs Do you have difficulty..... The WG short set uses ‘How much difficulty...?’ and the WHS, WHO/UNESCAP, etc. use ‘Do you have difficulty...?’ Is this an important difference or can we ignore it? Are there other similar ‘close’ differences that we should take into account?
- Response options – is this an issue or not?
- Choice and desire – how can we take this into account to ensure that responses we get on our measures reflect difficulties when the person needs to or wants to or has a choice whether to do an activity or not. ⁹

Way forward

The following are some steps that we need to take in order to move concretely on the extended sets:

- Discussion on the proposed sets and modifications required
- Compile the sets (I have avoided using the term ‘develop’ here to allow for us to creatively use what is already available).
- Building an evidence base for these sets: this entails two aspects:
 - What domains are necessary for each set
 - How do the different sets work in relation to their intended purpose for different data users
- Developing the guidelines for using the sets and determining who the data users are likely to be.

Margie Schneider with assistance of comments from members of the extended sets workgroup
11 September 2007

⁹ The CHIEF questionnaire and the Eurostat questionnaire and the new questionnaires being developed in France get over the problem by using the individual’s need or desire to participate as the reference point, not the actual participatory performance itself. If people do not need to or want to use transport then it is not a barrier to participation irrespective of the transport facilities available in a country.

Appendix A: Description of the sets for Proposal 1

Sets to collect data on functioning and disability

a) Parsimonious set

The proliferation of initiatives over the last decade on measurement of health and functioning is testimony to the need for some means of measuring the health state or functioning in a population to use as a general monitoring tool. The work of the WHO/UNESCAP, Budapest Initiative and Eurostat, have looked into this in some detail. Results from the WHO/UNESCAP and World Health Survey (WHS) suggest that there is a parsimonious set of questions that can be identified. The WHO/UNESCAP and WHS results suggest that it is not necessary to ask about hearing as well as communication as there is no advantage in asking about both of these domains. [Get detailed WHO/UNESCAP results from the pilot in 5 countries.]

This set would take those results and develop the set based on these. The set would be more detailed than the Short Set and would include some basic as well as some more complex activities. The set would include possibly more than one question per domain (e.g. far and near vision asked separately).

This set would not ask any detailed questions on environment beyond what is explicitly included in the question wording (e.g. vision with use of glasses, hearing with use of a hearing aid). Thus it will not be possible to determine exactly the role of environment in the responses people provide.

b) Detailed set that includes domains not covered in the parsimonious set

This set would provide information that can be used to determine the prevalence of all types of activity limitations as well as the role of micro level environmental factors on these difficulties. The domains covered would include those not included in the parsimonious set, such as hearing in the WHO/UNESCAP and WHS examples provided above.

Particular domains noted as important to include are:

- Learning
- Upper body mobility
- Psychological and emotional functioning (these are found in body functions rather than the A/P classifications of the ICF and so should be rephrased to ask about interpersonal interactions and relationships; decision making, handling of stress, etc.)
- Domestic activities
- Ability to carry out the tasks and actions required to engage in education, employment and community/social life.

In addition this set would ask about difficulties people have in doing these activities both with and without assistance (technical and/or personal) for those activities where this is possible (Cf appendix B for some discussion of this issue).

A few questions on the meso and macro environments would be included to determine in a general sense:

- Attitudes of others in household and community
- Access to services that are needed
- Extent to which barriers in the environment make it difficult for the person

This set would require some work to:

- Decide on the list of questions, their wording and response options using the short set and parsimonious sets as a basis to start from and adding to cover the required domains.

- Decide which questions can be asked in relation to micro environment (i.e. with and without assistance) and which cannot (more complex activities).¹⁰
- Decide whether the use and availability of assistive devices and personal assistance should be included as specific questions
- Structure the module of questions in an order that is logical.

c) Detailed set (as for set b) with detailed environment questions

This would be the same set as for the detailed set described in b) above. The additional questions would be questions on the environmental barriers and facilitators that may or may not have an impact on the person's functioning. The work of the Craig Hospital on their Inventory of Environmental Factors (CHIEF) would be a good starting point to see how to construct this module. Questions from the CHIEF or similar ones have been used or are being used in national surveys (e.g. SINTEF survey in Zambia and current survey in Tanzania and other studies) where these data can be used to analyse the way these questions are working. (See Appendix C for these questions.)

In addition, there are question sets developed that ask about the effect of the person's usual environment on different activities. (It's not clear where this set comes from as used in the Tanzanian questionnaire.)

Set for Personal and other factors

This set would be a complementary set of questions that are required to provide a holistic picture of what the person's context is. The information required includes the following:

- Age of onset, cause and: this is important as there are some significant differences in experiences arising from an early vs late onset of difficulty. These can be asked in relation to the health condition, impairment, activity limitation or participation restrictions. However, the most feasible one to ask about is for activity limitations. This is because, for
 - health conditions and impairments, responses reflect access to health care services that provide diagnoses
 - activity limitations, responses reflect a person's experience
 - participation restrictions, responses reflect the role of environmental factors and this is not a constant feature of a person's experience.
- Frequency and duration of the difficulty: e.g. Frequency = does the problem occur on an hourly, daily, weekly, etc. basis? And duration = how long has the problem lasted – days, weeks, months, years?
- Pain is a body function and has significant effects on a person's functioning. The measurement of pain is very difficult and in the context of self report modules would be asked in relation to its duration, intensity, and frequency and overall impact on functioning or impact on specific domains. Intensity of the difficulty would most likely be related to the level of pain reported.
- Level of distress: while distress is not an aspect included in the ICF framework, it could be useful information to include. The Perceived Impact of Problem Profile (PIPP)¹¹ uses questions on the impact of the health condition on a person's functioning in a number of domains as well as the distress caused by this impact. A scale of 1 (no distress) to 6 (extreme distress) is used in the PIPP.

¹⁰ This approach has been used in a number of studies so far (cf SINTEF living conditions surveys, South African national baseline survey on disability, and interviews with women living with arthritis) and the consistent picture across all these is that the reported severity of difficulty is always worse without than with technical and/or personal assistance. These suggest that people are easily able to provide responses that make this distinction. However, it is not clear whether people are as clear about the effect of environmental factors for more complex activities – e.g. whether they are not able to work because of accessibility and attitudinal barriers or because of their own limited ability to maintain work.

¹¹ See Pallant, J.F., Misajon, R., Bennett, E., & Manderson, L. (2006). Measuring the impact and distress of health problems from the individual's perspective: development of the Perceived Impact of Problem Profile (PIPP). *Health Qual Life Outcomes*, 4:36, <http://www.hqlo.com/content/4/1/36>