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WORLD HEALTH ORGANIZATION MEETING ON THE INTERNATIONAL CLASSIFICATION OF IMPAIRMENTS DISABILITIES AND HANDICAPS

December 7-10, 1993
Pan American Health Organization Headquarters
525 23rd Street, Northwest
Washington, D.C. 20037

Executive Summary

In its capacity as World Health Organization Collaborating Centre for the Classification of Diseases and Health-related Classifications for North America, the National Center for Health Statistics hosted a WHO-sponsored meeting on revising the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), December 7-10, 1993 at the Pan American Health Organization, Washington D.C. This was one in a series of international meetings being held as part of 1990's revision effort. Over 30 experts in disability classification and statistics from 10 countries considered proposals for revising the ICIDH, with special emphasis on mental health. About 30 additional observers from the USA attended the first day of the meeting (December 7), and expressed their willingness to participate in the revision process.

Agreement was reached on a tentative schedule of international meetings towards the revision of the ICIDH. Formalization of the classification will follow usual WHO procedures. It is anticipated that a revised proposal can be finalized for the 50th anniversary of WHO - and the 18th anniversary of the ICIDH - in 1998, and formally issued in 1999. The proposed international meetings (see Annex I) will focus on substantive ICIDH revision themes, as follows: 1994, children and special groups; 1995, policy relevance; 1996, relevance to developing countries; 1997, topics arising from earlier work and final agreement towards a revised draft. Four groups were established to focus on particular problem areas in the classification, with a focal role assigned to Collaborating Centres as follows:

Behaviour and Development (a.k.a. Mental Health) - NCHS (North America)

Sensory, Perception and Communication Functions - CTNERHI (France)

Movement - WCC (Netherlands)

Other and crosscutting concerns - Uppsala (Nordic countries) is considering this

WHO should ensure technical reviews and overall coordination of the process in cooperation with collaborating centres and relevant IGOs and institutions. In addition, it was agreed that the Collaborating Centres would continue their role in revising the various planes of the classifications (Impairments: CTNERHI; Disabilities: WCC; North American Collaborating Centre: Handicap), and that taxonomical guidelines would be prepared for use during the revision process.

At a preliminary meeting held on December 6th, dealing with problems of statistics and surveys on disability and the use of the ICIDH therein, it was recommended that such use be monitored jointly by UNSTAT and WHO.

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Tuesday, December 7, 1993

Item 1. Opening ceremony

Dr M.C. Thuriaux, on behalf of WHO, opened the meeting by welcoming participants and observers. Dr Pedro Castellanos, Regional Health Program Coordinator at the Pan American Health Organization, welcomed the group and expressed his wishes that conferees would make excellent progress on ICIDH revision in the conference facilities. Mr Robert Israel, Head of the WHO Collaborating Center for the Classification of Diseases and Health-related Classifications for North America at the National Center for Health Statistics, also welcomed the group, and emphasised the recent inclusion of ICIDH study and revision in the terms of reference of the NCHS. The NICHS was pleased to have this opportunity of introducing the ICIDH to US observers and thus facilitate the latter's potential contribution to the ICIDH revision process.

Items 2-3. Election of officers, adoption of agenda, introduction of participants and Observers

Dr M. de Kleijn-de Vrankrijker proposed Dr G. Hendershot to chair the meeting; Dr M. Bartley was nominated as Vice-Chair. Ms A. Furrie and Dr J. Peters agreed to serve as rapporteurs. The agenda (SES/ICIDH/93.1) was approved, item 19 being moved up to December 9. All participants were asked to introduce themselves (SES/ICIDH/93.2), and observers in particular were asked to mention their major activities related to the ICIDH and their potential contributions to the revision process (SES/ICIDH/93.17).

Item 4. The ICIDH: history and prospects

Dr M.C. Thuriaux provided an overview of the development of the ICIDH (SES/ICIDH/93.4). The extent of interest in the classification can be measured by its diversity of applications and the number of languages in which it is now available, the most recent version being Swedish. The commitment to undertake the first revision of the classification was arrived at in Zoetermeer, the Netherlands, in March, 1992 (SES/ICIDH/93.31).

Item 5. ICIDH concepts and structures

Dr E. Badley provided an overview of the concepts and structures (SES/ICIDH/93.30), describing the three planes of the classification and their interaction. She outlined some of the difficulties encountered in the use of the ICIDH and the main issues which should be addressed in the revision process, such as definitions, the borders between the planes of classification, clarification within each plane, and the further development of a conceptual model.

Item 6. Uses and users of the ICIDH

Dr M. de Kleijn-de Vrankrijker reviewed applications in at least 31 countries, in areas such as health care, social security, employment, rehabilitation, surveys, research, documentation, policy, education and training, mentioning examples of work in various professional groups (SES/ICIDH/93.6 and 93.7). There are at present 14 published translations of the ICIDH, and more are in preparation (SES/ICIDH/93.32). She identified various centres and organizations that have published ICIDH material, such as the Dutch WCC, which has a list of over 1 100 ICIDH publications (SES/ICIDH/93.5) and distributes information on them, along with the ICIDH newsletter *Voorwerk*, issued in English and Dutch.

Item 7. The ICIDH in North America

Ms A. Furrie (Statistics Canada) discussed the H portion of the ICIDH; improvements in this area, reflecting the needs of persons responsible for developing social and economic policy, would help convince organizations of and for persons with disabilities who are not currently using the ICIDH that it is a useful tool for their applications. The national statistical database on disability issues at Statistics Canada uses the concept of disability from the ICIDH, as operationalized through the Activities of Daily Living. These questions are supplemented with questions to identify persons with learning disabilities, intellectual disabilities, and disabilities as a result of a mental health problem or condition. Impairment and/or underlying health problems are also included, as is a measure of severity. The focus of the database is a "barriers data", used by policy departments at the federal and provincial level to monitor social and economic policy. Organizations of and for persons with disabilities were instrumental in the development of the questions to identify persons with "mental" disabilities and also had significant input the development of the topic areas on barriers.

Dr P. Fougeyrollas described the activities of the Canadian Society of the ICIDH, a non-governmental organization for the promotion of the use of the ICIDH throughout Canada (SES/ICIDH/93.21), and mentioned a 15-minute ICIDH-based film (*On equal terms*) produced in French and English by the society (see Wednesday 8 December).

Dr P. Placek provided an overview of four documents (SES/ICIDH/93.10, .11, .12, and .13) describing work in the US. Although the term "Handicap" is negatively value-laden in the United States, the word is used by more than 30 U.S. organizations that represent persons with disabilities. A number of automated ICIDH applications including the Jose Alcamí program (Spain), the Person-to-Job Match (Netherlands), the UN data-base on disability (DISTAT), and the Blue Cross of California applications for therapy service beneficiaries were described, as were other specific applications of use of the ICIDH.

Ms G. Swanson provided a short demonstration of the automated application of Blue Cross of California, using the disability coding structure of the ICIDH (SES/ICIDH/93.26). She provided a more in-depth demonstration on the following morning (see Wednesday 8 December).

Mr R. Israel moderated a variety of comments by participants and observers. Most of the questions requested elaborations of the speakers.

Wednesday, December 8, 1993

The day started by the showing of a film illustrating the concepts of ICIDH and prepared by the *Office des Personnes Handicapées du Québec*, and by a presentation of an automated application of Blue Cross of California, using the disability coding structure of the ICIDH (see item 7).

Item 8. The role of the National Center for Health Statistics (NCHS)

Dr M. Feinleib, NCHS Director, described the activities of the National Center for Health Statistics as they related to disability statistics and the ICIDH (SES/ICIDH 93.14). He acknowledged with pleasure the opportunity to participate in the revision process of the ICIDH and welcomed Canada as a partner in the North America Collaborating Centre's activities. He summarized the increasing involvement of NCHS in disability classification, including:

a. the December 1992 NCHS/United Nations "Workshop on Classification and Measurement in Population-Based Surveys";
b. the September 1993 NCHS/U.S. National Committee on Vital and Health Statistics "Special Meeting on the ICIDH";
c. the September 1993 NCHS initiation of a U.S. training program on the ICIDH;
d. the 1994-1995 National Health Interview Survey on Disability, which, funds permitting, will be back-coded to the ICIDH.

Dr Feinleib stressed the need for a common approach to the classification of disability; the use of the ICIDH would be instrumental in the discussions of health care reform in the USA. He closed the first day of the meeting by inviting all present to a reception in the PAHO facilities.

Item 9. General procedures for revision: introduction

Dr M.C. Thuriaux submitted an overview of the proposed activities for the revision of the ICIDH. These proposals were further discussed on December 10; the outcome of these discussions was a detailed operating plan covering five years, which is outlined under items 20-21 and in Annexes I-II.

Item 10. Use of the ICIDH for mental health policy, programmes, and research

Dr F. Chapireau discussed the development of an ICIDH-compatible classification of disablement for children and teenagers with mental disorders. The ICIDH met most of the needs for this new classification. However, the group encountered problems when some terms were applied directly to child psychiatry. To address these issues, some wording was changed, some items were deleted, and some missing items were added. These alterations did not change the compatibility of the new document with the ICIDH (SES/ICIDH/93.16).

Item 11. Previous work on the revision of the mental health component

Dr B. Üstün outlined experiences in the development of ICD-10 classifications for mental disorders (SES/ICIDH/93.28), and suggested that similar strategies might be useful in revising the ICIDH. He suggested that the ICIDH structure for mental disorders be linked to diagnoses and assessment instruments. Additional suggestions included:

- I, D, and H categories should be constructed to be mutually exclusive, classification rules should be clearly specified and the purpose of each category clearly understood.
- The classification should be meaningful in different cultures, rely on agreement with users, serve national classifications, be attractive to practitioners through linkage to existing databases, respect different languages, and be compatible with ICD-10 and related classifications.
- The basic I, D, and H concepts are applicable to mental health, but improvement in the definitions with respect to content would be helpful. With respect to Impairments, observable functions should be the basis for classification, since the distinction between structure and function at the organ level for mental disorders is not clear. With respect to Handicap, the contribution of social circumstances and of individual factors should be clarified.
- There should be a separate assessment of modifying factors including the psychological reaction to disablement, social support, and burden on the family.
- The course and severity of a condition should be coded; this should not be merely a list, but should expand into a system, as is the case in the mental health applications of ICD-10.
- Several versions of the ICIDH should be made available for use in different settings including primary care, clinical care, specialty settings, and research.

The following points and issues were raised in discussion:

1. More time than is currently scheduled for the revision process would probably be required to achieve the above.
2. Some overlap between planes is unavoidable. If the three classifications are used separately, overlap may even be needed so the impairment is comprehensive when viewed from the point of view of the body, disability is comprehensive when viewed from the point of view of the person, and handicap is comprehensive when viewed from the point of view of society.

3. There is a relationship between overlap and definition of boundaries. A basic principle of classifications is that boundaries between categories, which may not exist naturally, are constructed to separate categories. Once boundaries have been drawn, defining items correctly is essential and requires saying what something is and what it is not. This clarifies items, minimizes overlap, and reduces the issue to deciding on which side of the boundary an item lies.
4. If the term "role" were dropped, understanding the handicap plane might be easier. Use of the words "disadvantage", "circumstances", and "relationships" may assist in understanding what a handicap is and what it is not.

Item 12. Current status on the mental health component in North America

Dr C. Kennedy provided an overview of the current status of mental disorder-related disability activities in the United States (SES/ICIDH/93.25). She described the deliberations of a working group which examined mental health applications in the United States.

Item 13. Overview of areas for proposed revision in the area of mental health

Dr S. Brown provided an overview of the areas for proposed mental health revision based on previous discussion in this and earlier U.S. ICIDH meetings (SES/ICIDH/93.18 and SES/ICIDH/93.23). He suggested that at least three workgroups convene within the present meeting to inventory revision proposals affecting mental health:

Workgroup I : Amplification of taxonomy and conceptual framework
Workgroup II : Interface of ICIDH with ICD-10 Impairment
Workgroup III : Disability, Handicap, and crosscutting or complex concepts

Item 14-15. Mental health workgroups

Ms A. Furrie assigned participants to Workgroups, asking them to present their recommendations the next day. The three workgroups deliberated on their respective topics throughout the remainder of the afternoon and on the morning of December 9.

Thursday, December 9

Item 16. Presentation and discussion of workgroup proposals (See also Annex III)

The three workgroups provided an overview of their discussions (summary provided in Annex III); general recommendations for the three groups included:

1. The ICIDH introduction should be as specific as possible. Future revisions should be thoroughly reviewed to reduce ambiguity and misinterpretations. This should be done through group consensus and should include translations and back-translations.
2. The revision working groups should review the "survey of criticisms" prepared by the WCC (SES/ICIDH/93.8 and 93.9).
3. The wider uses of a classification system should be considered.
4. Biases should be eliminated.
5. The revision process should continue to involve persons with disabilities.
6. Guidelines on applications of the ICIDH should cover ethical issues.

General taxonomical guidelines should be prepared early as a working tool for the Working Groups for the revision of the ICIDH (see Annex IV).

Items 17-19 Not discussed.

Items 20-21 Conclusions: proposals for the revision process

A general discussion on proposals for the revision process, including items outlined in document SES/ICIDH/93.9, and in the light of work during the present meeting, led to the outline of procedures summarized hereafter.

The revision process involves:

- harmonization of modifications in each of the planes (impairment, disability and handicap)
- area-specific revision activities - to be undertaken by area-specific working groups.
- support and administrative coordination of revision activities - to be undertaken by WHO;
- ongoing overall technical review in cooperation between WHO and participants in the working groups.

1. Harmonization of proposals for modifications within the three planes of the ICIDH.

Collaborating Centres will continue their role in revising the various planes of the classifications (Impairments: CTNERHI; Disabilities: WCC; Handicap: North America Collaborating Centre). The Canadian Society for the ICIDH, as part of its work within the North America CC, will continue to compile publications on the impact of environmental factors on the disablement process.

2. Area-specific activities for technical revision.

The following broad areas were identified:

- Behaviour and Development (a.k.a. Mental Health);
- Sensory, Perception and Communication functions;
- Movement;
- Other, and crosscutting concerns (in close cooperation with the previous three groups, whose work will largely serve as a basis for the identification of specific work areas).

For each area, a working group will be established, drawing on the resources of experts, Collaborating Centres and other institutions at national and international levels. One of the established Centres will serve as focus for the relevant area, with participants from other Collaborating Centres and relevant institutions (IGOs, organizations representing persons with disabilities) as appropriate. A WHO anchor person will serve for each working group. Proposed anchors in WHO and focal collaborating centres/institutions are listed hereafter.

Behaviour and Development (a.k.a. Mental Health)
Focal CC : NCHS (USA)
WHO anchor : MNH (Dr Ustün)
Sensory, Perception and Communication Functions
Focal CC : CTNERHI (France)
WHO anchor : PBL (Dr Thylefors)
Movement
Focal CC : WCC (Netherlands)
WHO anchor : RHB (Dr Goerdt)
Other, and crosscutting concerns
Focal CC : Nordic centre is considering this
WHO anchor : SES/HST (Dr Thuriaux)

Monitoring the use of ICIDH by countries for statistical purposes is an essential step in assessing the quality of revision proposals and in assessing ICIDH use through activities such as coding and back-coding. The work of UNSTAT in the development of the International Disability Statistics Database (DISTAT) has highlighted the usefulness of monitoring the use of the ICIDH in national surveys, censuses and registries and in estimating the prevalence of disability worldwide. At a meeting held in Washington D.C. on 6 December 1994 prior to the present meeting, it was agreed that UNSTAT should continue its important contribution to the revision process through the development of DISTAT as a tool for monitoring the use of ICIDH for statistical purposes, in collaboration with WHO.

Problems of overlap will be settled by mutual agreement. The Nordic centre has already proposed to initiate analysis of ICIDH overlaps with ICD-10. The North American Centre was asked to consider possibilities for an alternative term for "handicap". The work of each group will involve several phases as outlined in Annex II. An early task will be the development of taxonomical guidelines to be used during activities within each of the technical areas. Drs Hirs, Lurie and Cooper agreed to prepare these (Annex IV).

Participants from all specific areas and working groups should meet regularly during the revision process in order to address issues requiring input from more than one area (such as special population groups, the nature and determinants of handicap, impact on policy, and others). To this effect, Work-in-progress reports will be regularly prepared for discussion at those meetings; individual discussions and meetings may also take place on an *ad hoc* basis.

Proposals for revision should be based on the analysis of practical applications rather than on theoretical considerations, and include the cooperation of United Nations and other intergovernmental organizations and of suitable organizations which represent persons with disabilities. For its part, WHO will ensure that NGOs in official relation with WHO are encouraged to participate in the ICIDH revision at the international level. Particular attention should be paid to the role of environmental factors in the process of disablement.

In addition to the list of major working papers on Disability prepared by the Netherlands Collaborating centre, lists of the major working papers currently available will be prepared by the collaborating centres working on Impairment (France) and Handicap (North America) and forwarded to each working group for use in their revision process. The relevant review of ICIDH critiques prepared by the Dutch Collaborating centre (SES/ICIDH/93.8) should be updated by contributions from other areas. Drs Deveau (France), Komarov (Russia), Nilsson (Nordic countries), Frappola (South America) have agreed to assist in this.

3. *Support and administrative coordination of revision activities.*

WHO secretariat will ensure coordination in order that the revision process respect the overall WHO principles and rules. This will include the following activities (dates are indicative):

from 1994 - inform governing bodies of WHO, international NGOs and relevant professional groups including professional journals of the process for revision of the ICIDH;
- solicit the cooperation and support of relevant NGOs for the revision process;
- facilitate communication between participants in the revision process;
- inform the annual meetings of heads of collaborating centres on ICD and health-related classifications and gather their comments;
- prepare annual meetings of the participants in the revision process, including assembling the work-in-progress reports provided by each working group;
- disseminate the conclusions and results of such meetings;

from 1995 - prepare successive consolidated drafts of the ICIDH revision based on work-in-progress reports and comments received;
- obtain and supervise the preparation, dissemination (at meetings of the participants in the ICIDH revision process and elsewhere) and revision (in the light of comments received) of documents complementary to the I, D, H classifications proper, such as:
  - introduction to the revised ICIDH,
  - guidelines for users,
  - position papers on handicap, environmental factors, as appropriate;

from 1997 - prepare a draft ICIDH for submission to official review body (Revision Conference or other);

from 1998 - prepare the revised ICIDH for the WHO governing bodies;

from 1999 - submit the revised ICIDH to WHO governing bodies;
- set up mechanisms for maintenance and updating of the revised ICIDH.

4. Ongoing overall technical review group

WHO secretariat, in cooperation with Collaborating Centres involved in each of the area-specific working groups, heads of Collaborating Centres for Health-related Classifications, and representatives of relevant IGOs (*e.g.*, UNSTAT, UNICEF, UNESCO, ILO) will regularly review work-in progress to provide suggestions and adjust the working plans as appropriate.

Formalization of the classification will follow usual WHO procedures. It is anticipated that a revised proposal can be finalized for the 50th anniversary of WHO - and the 18th anniversary of the ICIDH - in 1998, and formally issued in 1999. The process of revision for the ICIDH is thus under way. It will be based on a review of the experience of users through reports and documents describing its use, and on consultation with expert representatives from relevant disciplines and through representation of experiences from countries in the various Regions of WHO. The cooperation of international and nongovernmental organizations - including organizations of people with disabilities - which deal with different aspects of disability will continue to be sought.

Closure

Dr Hendershot closed the meeting after thanking all participants.

Annex I: proposed ICIDH-specific meetings, 1994-1999 (indicative)

1994 Netherlands, November 14-18.
Review of minutes from earlier meetings in Zoetermeer and Washington
Presentation and review of area-specific Work-in-progress reports and problems
Review of overall developments on Impairment, Disability, Handicap

General topic to be considered: children and special groups

1995 France
Review of 1994 meeting minutes
Presentation and review of area-specific Work-in-progress reports and problems
Review of overall developments on Impairment, Disability, Handicap
Selective review of initial draft of revised ICIDH

General topic to be considered: policy relevance of the ICIDH

1996 No definite proposals, possibilities include Jamaica or other developing country; (Canada or an African country or other may also be considered)
Review of 1995 meeting minutes
Presentation and review of area-specific Work-in-progress reports and problems
Review of overall developments on Impairment, Disability, Handicap
Selective review of draft ICIDH, introduction, user guidelines, etc., as appropriate

General topic to be considered: relevance to developing countries.

1997 Other site, Geneva or a developing country
Review of 1996 meeting minutes
Presentation and review of area-specific Work-in-progress reports and problems
Review of overall developments on Impairment, Disability, Handicap
Review of draft ICIDH, introduction, user guidelines, etc., as appropriate

General topic to considered: possibly "severity gradings", or other arising from revision work

1998 Review (Revision conference or other equivalent), WHO/HQ, Geneva

1999 Submission to governing Bodies and publication of ICIDH-2

Annex II: Phases of area-specific work - general guidelines (see also document SES/ICIDH/93.9).

Phase 1 - Enquiry

develop work plan
review critiques
identify areas to be modified
propose modifications
work-in-progress report (summer 1994) to be sent to WHO for meeting of ICD heads of ICD collaborating centres and for discussion at ICIDH revision meeting (Netherlands, November 1994)

Phase 2 - Draft (c1995)

circulate draft to outside observers
incorporate comments received in a consolidated draft for the area concerned, as well as the
prepare the phase of testing and comment
identify testers and commentators
draft covering texts
establish procedures to deal with comments
Work-in-progress report (summer 1995) to be sent to WHO for meeting of ICD heads of ICD collaborating centres and for discussion at ICIDH revision meeting (1995)

Phase 3 - testing and comment (1996/7)

undertake field testing as appropriate
incorporate results and comments in a father draft
iterative modifications of proposals as needed
Work-in-progress reports (summer 1996 and 1997) to be sent to WHO for meeting of ICD heads of ICD collaborating centres and for discussion at ICIDH revision meeting (1996 and 1997)

Phase 4 - formalization of classification.

Phase 5 - maintenance of classification.

Annex III: Summary of discussions, Washington working groups on mental health.

Workgroup I: Amplification of Taxonomy and Conceptual Framework

(Taxonomy)

- Coding severity, duration, and outlook are important, sometimes essential, but should be an adjunct to the classification system, not part of it.
- There should be no implied ratings in the I code unless necessary for special circumstances.
- The impairment classification is heterogeneous and could be simplified (e.g. left and right for hearing, vision, skeletal - see document SES/ICIDH/93.24)
- Consider reserving a space or field for coding severity, duration, and outlook.
- A procedure for multiple codes for individuals could be developed
- Modifying factors are important but should not be part of the classifications. It is desirable however that they be incorporated in developing assessment schedules.

(Definitions)

- Focus should be on description of domains and concepts, and on working rather than formal definitions, listing what an item is and what it is not.
- The formal wording of definitions should be left until later
- The shaping of domains should be an iterative process grounded in attempts at operationalization.

There was general agreement that the domain of impairment is "body/organ", the domain of disability is "person", and the domain of handicap is largely "social", and that definitions should be grounded in these domains. There was partial agreement that the use of terms such as role, disadvantage, and environment should be avoided to minimize misunderstandings.

- Handicap is not disability or impairment, but rather involves specific social roles, and norms, the environment, barriers, and expectations of individuals.
- The Handicap domain should not be culture-dependent and should not include references to the reasons or the cause of the handicap (specific disability or specific diseases). In other words, the H classification should be able to stand independently of the other two classifications.
- The extensional definition of handicap includes activities that are more or less characteristic in any culture and include: moving around effectively, being normally independent, occupying time, participation, socioeconomic interaction, and interaction with surroundings.

(Framework)

- Handicap is fundamentally different from disability. The main cut between the two should not be level of complexity of activities. Handicap represents a different perspective, a difference in kind. It is a "social phenomenon".
- The approach to the framework/conceptual models should be written as clearly and in as much detail as necessary to avoid misunderstanding and misinterpretations.

Minority views:

1. We need a separate additional classification of "social roles" (for mental health purposes)
2. Handicap is a reflection of social sub-roles or a "summary" of social performance incorporating many roles.
3. The conceptual model may need to be extended with a "fourth" dimension for social roles.

Workgroup II: Interface of ICIDH with ICD-10; Impairment

(ICD Interface)

- The ICD and ICIDH have different aims
- The apparent overlap of ICD/ICIDH is not a problem since symptoms are used for diagnosis.
- There should certainly be no overlap in headings.
- It is not always clear whether items such as "Loss of structure" belong to the ICD or to the ICIDH; for the time being, the ICIDH should host "Loss of structure" when this is not included in the ICD.
- Diagnoses should not occur in the ICIDH. Dr Nilsson volunteered to examine the ICD and ICIDH for overlap and to prepare a listing of such.

(Impairment)

- The division into two major categories (intellectual and other psychological impairments) is not satisfactory.
- For developmental disabilities-diagnosis, consequences should be coded in the ICIDH.

The group also examined various proposals which had been made at meetings in Mannheim and Paris regarding mental health impairments and disabilities; these proposals need editing before they can be further considered - Dr C. Kennedy volunteered to revise and circulate them.

Workgroup III: Disability, Handicap, and crosscutting or complex Concepts

(Disability)

- Social role "disabilities" should be moved to the third level. Some such "disabilities" are found in the current "disability" items 17-19.
- Outlook scales should be evaluated for usefulness and comprehensiveness. How many scales are needed?
- Inferences of disease/impairment in disability codes and descriptions must be avoided.

(Handicap)

- A new term is needed for the third level. "Social participation" was suggested but did not meet with unanimous approval.
- This third level is a result of interaction between individual (personal characteristics) and environmental (social and physical) factors.
- "H" is not a list of environmental factors, but such a list is needed. A classification of environmental factors should be developed as a supplement to the ICIDH.

General Recommendations

1. The ICIDH introduction should be as specific as possible. Future revisions should be thoroughly reviewed to reduce ambiguity and misinterpretations. This should be done through group consensus and should include translations and back-translations.
2. The revision working groups should review the "survey of criticisms" prepared by the WCC (SES/ICIDH/93.8 and 93.9).
3. The wider uses of a classification system should be considered.
4. Biases should be eliminated.
5. The revision process should continue to involve persons with disabilities.
6. Guidelines on applications of the ICIDH should cover ethical issues.

Annex IV: Proposed taxonomy guidelines

Introduction

The basic philosophy in terminology is that we do not have as many words in our language as we have concepts in our knowledge. Standard classification may help us to cope with this problem: we can agree on the use of one term for each of those concepts we wish to standardize, but do not need to standardize every word for every concept or every entity. Three steps can be considered in the construction of a classification of concepts.

Select entities and attributes belonging to the domain or subject field we want to classify.

If the main purpose of the ICIDH is to order and count phenomena relating to the individual, the taxonomic requirements of the ICIDH may be restricted to the individual person and his/her characteristics. Objects which are not under control of the individual person, such as physical and social environment, do not belong to this IDH domain, nor do other intrinsic characteristics of the individual, like disease, age or sex, for obvious reasons. However external factors, like environment and role, may become characteristics of the handicap of a person as far as these factors influence the individual's universe. But then, so do the life perspective and personal beliefs of the individual, insofar as these fundamentals influence coping with I, D, H.

Select concepts and relationships which construct the classification required for a specific purpose.

Taxonomic requirements for ICIDH may be met by three independent hierarchies of interference with individual performance:

- at structure/function organizational level (below the individual level);
- at the individual level;
- at the level of interaction with society, above the individual level.

Select a term which has a one-to-one relation to each concept.

In English, we only have to cope with the acceptability of terms such as impairment, disability and handicap. The concepts rather than the words themselves should be translated.

Guidelines (1-12)

Domain of the ICIDH (1-3)

1. The classifications should encompass the whole range of impairments, disabilities and handicaps, according to the agreed concepts; the current working definitions (dealing respectively with psychological/physiological/anatomical structure or function; with skills/activities, and with disadvantages) should be kept for the time being.

2. The ICIDH should be limited to impairments, disabilities and handicaps:

   a) only those symptoms and disorders which correspond to impairments should be included - diseases coded as such in the ICD should not appear in the ICIDH;
   b) other data elements (such as age and sex) should be coded separately and not incorporated into the ICIDH codes;
   c) lists or classifications of environmental or other external factors for use alongside the ICIDH codes are important adjuncts, but not in themselves part of the ICIDH.

3. Categories of impairments, disabilities, or handicaps which cannot be measured or assessed should be avoided wherever possible.

General classification structure (4-7)

4. Every impairment, disability or handicap must have a single, well defined place in the list of categories.

5. Categories belonging to the same plane (impairment, disability or handicap) should be mutually exclusive (categories in different planes are mutually exclusive by definition).

6. The three planes of the ICIDH should be regarded as related classifications, although each can be viewed (and used) as an independent classification. There should be no overlap among the three planes of the ICIDH (i.e., impairments should not be included in the disability or handicap codes, etc.).

7. The revised ICIDH should be as easy to use as possible. This can be achieved by standardizing definitions and terminology and through adequate indexing and annotations for users of all levels of sophistication.

Classification principles (8-12)

8. Each of the classifications should have a hierarchical structure with subdivisions. The classifications should retain the ability to identify individual conditions separately, and to allow presentation of data for broader groupings of conditions.

9. Impairments, disabilities and handicaps of particular public health importance should have their own categories.

10. Impairments, disabilities and handicaps that occur frequently should have their own categories.

11. There should be residual categories (other and unspecified) for "other" and "miscellaneous" conditions that cannot be allocated to more specific categories. The number of conditions assigned to residual categories should be kept to a minimum.

12. The ICIDH should leave room for expansion. Leave "empty" code numbers to be filled if and when need arises and develop mechanisms for periodic updating.

PROPOSED TIME TABLE AND AGNEDA

Provisional Agenda revised December 2, 1993

World Health Organization Meeting on the International Classification of Impairments, Disabilities and Handicaps

Pan American Health Organization
525 Virginia Avenue, N.W.
Washington, D.C.
Room C, 2nd Floor
7-10 December 1993

Tuesday, December 7

REGISTRATION 8:30 AM

9:30 AM

1. Opening ceremony
2. Election of officers and adoption of agenda
3. Introduction of participants and observers

BREAK 11:00-11:20

4. The ICIDH: history and prospects ..... M. Thuriaux

LUNCH (on your own) 12:00

1:30 PM

5. ICIDH concepts and structures..... E. Badley
6. Users and uses of the ICIDH..... M. de Klein-de Vrannrijker

BREAK 2:30

2:50 PM

7. The ICIDH in North America
   Canada ..... A. Furrie
   United States ..... P. Placek
   Participant and observer comments, moderated by ..... R. Israel
8. The Role of the National Center for Health Statistics ..... M. Feinleib

RECEPTION: 4:30-5:30 P.M.

Wednesday, December 8

DEMONSTRATION OF ICIDH-RELATED PRODUCTS 8:30 AM

9:30 AM

9. General procedures for revision ..... M. Thuriaux
10. Use of the ICIDH for mental health policy, programs, and research ..... F. Chapireau

BREAK 10:40

11:00 AM

11. Previous work on revision of the mental health components ..... B. Ustun
12. Current status on the mental health components in North America..... C. Kennedy

LUNCH (on your own) 12:00

1:30 PM

13. Overview of areas for proposed mental health revision ..... S. Brown
14. Constitution of mental health workgroups... A. Furrie

BREAK 3:00

3:20 PM

15. Groups start work on mental health revision proposals

ADJOURN 4:30 PM

Thursday, December 9

9:30 AM

15. Workgroups continue to develop proposals on mental health

LUNCH (on your own) 12:00

1:30 PM

16. Presentation and discussion of workgroup proposals

BREAK 3:00

3:20 PM

17. Draft proposals for action on mental health revisions

ADJOURN 4:30 PM

Friday, December 10

9:30 AM

18. Review, revise, and adopt proposals on mental health

BREAK 10:30

10:50 AM

19. Establish groups for inter-meeting activities

LUNCH (on your own) 12:00

1:30 PM

20. Proposals for steering committee and workgroups agendas

BREAK 3:00

3:20 PM

21. Set agenda and provisional schedule for future revision meetings.
22. Closing ceremony

ADJOURN 4:30 P.M.

Annex VI

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Annex VII

PROVISIONAL LIST OF DOCUMENTS

SES/ICIDH/93.1	Proposed Agenda and Timetable
SES/ICIDH/93.2	List of Participants and Observers
SES/ICIDH/93.3	List of Documents
SES/ICIDH/93.4	The ICIDH: Overview and Review Process (Thouriaux)
SES/ICIDH/93.5	List of References in Relation to the ICIDH (Keerkens et.al.)
SES/ICIDH/93.6	Proposal for Adaptation of ICIDH by Five Dutch Health Professionals
SES/ICIDH/93.7	Revision of the ICIDH Speech and Language (Raaijmakers and Dekker)
SES/ICIDH/93.8	A Survey of Criticism about the ICIDH (Keerkens et.al.)
SES/ICIDH/93.9	Report by the Dutch Collaborating Centre for the ICIDH (Vrankrijker and Hirs)
SES/ICIDH/93.10	Applications of the ICIDH in the USA (Nieuwenhuijsen)
SES/ICIDH/93.11	Prospects of Computer-Based Patient Records Using the ICIDH (Placek)
SES/ICIDH/93.12	ICIDH Related Publications in the U.S. (Nieuwenhuijsen)
SES/ICIDH/93.13	Special Meeting on the ICIDH: U.S., Sept. 8, 1993 (Placek)
SES/ICIDH/93.14	The ICIDH: the Role of NCHS (Feinleib)
SES/ICIDH/93.15	Suggestions for Revision of ICIDH (Cooper)
SES/ICIDH/93.16	Use of ICIDH for Mental Health Policy, Programs, and Research (Chapireau)
SES/ICIDH/93.17	Observer Information
SES/ICIDH/93.18	Application of WHO ICIDH for Mental Health Statistics (Brown)
SES/ICIDH/93.20	The Conceptual Framework of the ICIDH (Chapireau/Council of Europe)
SES/ICIDH/93.21	Patrick Fougeyrollas reprints
SES/ICIDH/93.22	Mental Health Overheads (Cates)
SES/ICIDH/93.23	Overview of Areas for Proposed Mental Health Revision (Brown)
SES/ICIDH/93.24	Materials Used 12/8/93 by Group 2 Taxonomy (Kennedy/Ritchie)
SES/ICIDH/93.25	North American Task Force (Kennedy)
SES/ICIDH/93.26	Monitor Three Function Codes 12/8/93 Demonstration (Swanson)
SES/ICIDH/93.27	Mannheim, Germany meeting 28-30 June 1993 Report
SES/ICIDH/93.28	ICD-10 E and F Codes
SES/ICIDH/93.29	Proposed Definition Changes (WHO/NCH June 1993)
SES/ICIDH/93.30	The Genesis of Handicap...(Badley)
SES/ICIDH/93.31	Second Meeting on Updating ICIDH...Zoetermeer March 1992
SES/ICIDH/93.32	User and Uses of the ICIDH (Vrankrijker handout)
SES/ICIDH/93.33	Standard Rules on the Equalization...United Nations A/C.3/48/L.3 (Chamie)
SES/ICIDH/93.34	Time Schedule for Revision-Overheads (Thouriaux)