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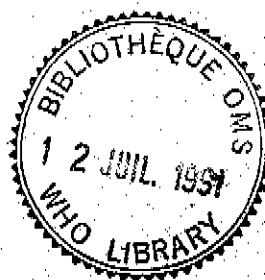
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HEALTH FOR ALL INDICATORS: DISABILITY

IDENTIFICATION OF INFORMATION
ON DISABLEMENTS IN ROUTINE STATISTICS
AND HEALTH INTERVIEW SURVEYS

Report on a WHO Meeting



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EUR/HFA TARGET 3

This activity was organized by the WHO Regional Office for Europe to promote work aimed at achieving the following target in the health for all strategy.^a

TARGET 3

BETTER OPPORTUNITIES FOR THE DISABLED

By the year 2000, disabled persons should have the physical, social and economic opportunities that allow at least for a socially and economically fulfilling and mentally creative life.

Index terms

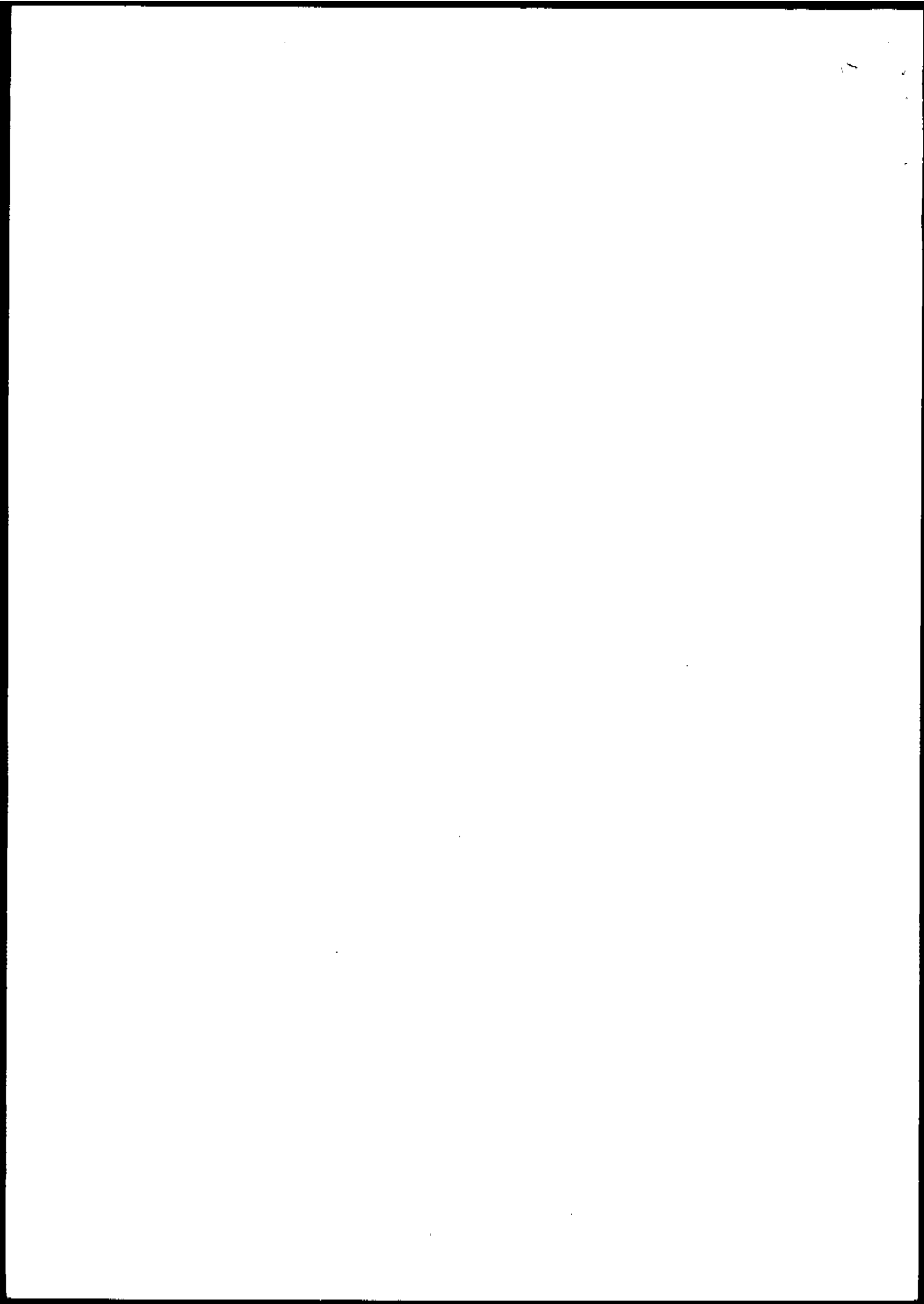
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HEALTH FOR ALL
HEALTH STATUS INDICATORS
HEALTH SURVEYS
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^a *Targets for health for all.* Copenhagen, WHO Regional Office Europe, 1985 (European Health for All Series, No. 1).

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Introduction

At the request of the Regional Office of the World Health Organization, a brainstorming meeting was convened at the Netherlands Central Bureau of Statistics on the issue: "Revision of health for all (HFA) indicators - disability". A list of the participants is given in the Annex 1. During this meeting information sources on disablements were identified in the light of the revision of HFA indicators and the evaluation of progress in health status in the European Region.

A discussion paper was presented, dealing with the following topics:

- scope of the meeting
- purpose of the meeting
- HFA indicators on disability
- extended information on disability
- sources of data on disability
- comparison of registration systems and surveys
- conclusions and recommendations.

Scope of the meeting

The regional health for all targets set forth the minimum progress the European countries must make in improving health by the year 2000 (1). As regards health outcomes the HFA strategy has four dimensions, involving action to:

- ensure equity in health
- add life to years
- add health to life
- add years to life.

As a consequence of the greying of the population, the improvement of life expectancy and the medical technological advancements, chronic conditions and disabilities are becoming major health problems in European countries. With respect to disabilities, "Adding life to years" and "Adding health to life" are the focus of attention in the HFA strategy. In this context the three following targets are notably relevant.

Target 2: By the year 2000, people should have the basic opportunity to develop and use their health potential to live socially and economically fulfilling lives;

Target 3: By the year 2000, disabled persons should have the physical, social and economic opportunities that allow at least for a socially and economically fulfilling and mentally creative life;

Target 4: By the year 2000, the average number of years that people live free from major disease and disability should be increased by at least 10%.

Progress towards HFA in the European Region has been assessed by means of monitoring exercises carried out in 1984-1985 (2) and in 1987-1988 (3).

The second assessment revealed significant progress in implementing HFA policy. With regard to targets 2, 3 and 4 it is stated that progress has been made towards reducing congenital diseases and disabilities. The assessment of the disabling effects of chronic illness, however, is still problematic. Because of differences in measurement techniques and data sources it remains difficult to compare the prevalences of reported disabilities. Disability rates vary considerably and are difficult to interpret. The value of these rates is considered questionable and at the end of the 1980s a more coordinated collection of data on disability on the European scale was proposed. "Much remains to be done to develop standard means of measurement that can be accepted and used by all concerned. New policies and programmes are being introduced, but otherwise there has been little or no progress so far as disability is concerned" (3).

The availability of some selected HFA indicators has been assessed on the basis of the country reports received during the second monitoring exercise (4). Data on indicators of disability proved to be collected by a few countries only; these data were, however, not directly comparable. Systematic identification and collection of data useful for many purposes have been recommended.

Purpose of the meeting

The evaluation of the monitoring exercises reveals that revision of the disability-related indicators is strongly needed in supporting the health for all strategy in "Adding life to years" and "Adding health to life". A database on disabilities is considered prerequisite for this revision. The specific aims of the meeting were formulated as follows:

- (a) to consider how to identify information on disablements in routine statistics and health interview surveys;
- (b) to consider how to report and record this information;
- (c) to recommend on the development of guidelines on creating databases on disablements.

HFA indicators on disability

Monitoring and evaluation of the HFA strategy are based on indicators defined as "variables that help to measure changes in the health situation directly or indirectly and to assess the extent to which the objects and targets of a programme are being attained" (5). For the purpose of the assessment of disabilities several indicators, marked as essential (E) or supplementary (S), were adopted in 1984 by the WHO Regional Committee for Europe (1).

- S 2.3 Measurement of independence in activities of daily living
- S 3.2 Percentage of disabled persons aged 15-64 engaged in regular occupational activities

- E 4.1 Number of disability days per person and per year, by level of restriction
- E 4.2 Percentage of the population experiencing different levels of long-term disability, by age and sex
- E 4.4 Absenteeism from work due to disease or injury
- S 4.5 Expectation of life free from disability
- S 4.6 Incidence and/or prevalence of selected major chronic conditions.

These indicators were tested in the regional HFA strategy evaluation in 1984-1985. In the light of its results, a revised list of indicators was worked out and adopted in 1987 (6). This revision resulted in some modifications:

- deletion of indicator E.4.4
- addition of a new indicator S.4.9: long-term incapacity for work.

The revised list was used in the 1987/1988 exercise to monitor the national HFA development. This second evaluation still revealed shortcomings and problems. In 1989 a meeting was convened to formulate recommendations on this topic (7). It was generally agreed that the distinction between essential and supplementary indicators was neither clear nor helpful and should be abandoned. The following suggestions for updating were made:

- deletion of indicator 2.3: activities of daily living are aspects of disability which can be included in 4.2;
- addition of a new indicator 2.5: proportion of unemployed persons;
- reformulation of indicator 4.6: only data on prevalence should be collected; specificity should be increased.

In the revision process of HFA indicators two procedures can be distinguished. The first focuses on the assessment of the relevance of indicators in the light of the targets of the HFA strategy. The second sets out with the assessment of the availability and usefulness of data sources of disability; the utility of data then supports the revision of HFA indicators. This second procedure was followed in the meeting on which this report is based. A whole range of databases could give information on disabilities and hence could provide the necessary materials for health planning.

Extended information on disability

To evaluate progress in the health status of the population, estimates of the crude disability rate are considered insufficient. Additional topics for analysis are required in order to interpret the situation of disabled persons and to influence future developments. In this context, Chamie (8) proposes an analytic framework on the basis of the topics that are regarded useful for

monitoring the United Nations World Programme of Action concerning Disabled Persons. She classifies the topics into four major areas for survey monitoring: demographic, socioeconomic, household and family characteristics, and descriptions of the disability - specific experience. The topics are provided in the following figure.

Fig. 1. Topics covered by censuses and surveys

Demographic

1. Age group and sex
2. Urban/rural residence

Socioeconomic

3. Educational attainment
4. Economic activity
5. Occupation/industry
6. Marital status

Household and family information

7. Household information
8. Family composition
9. Income (personal and household)

Describing the disability experience

10. Additional impairments
11. Age at onset
12. Cause of impairment
13. Disability status
14. Severity of impairment or disability
15. Special aids used
16. Services or treatment received
17. Special topics

Source: Chamie (8).

With reference to the work of Chamie the discussion focused on the classification and selection of relevant items.

Classification of disabilities

In health care and health policy several classification schemes of disabilities are used. The main schemes are the International Classification of Diseases (ICD) and the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (9).

The ICD is the instrument for classifying diseases, injuries and causes of death and hence does not provide the necessary information on disabilities. The introduction of the Z-code in the ICD-10 is considered a

contributing tool in providing additional information. The Z-code presents the non-medical reasons for contact with medical services. A difficulty of this code is that it locates problems more in the local circumstances of the health care sector and less in the disability status of individuals. Some headings however are seen as potentially relevant, not for the classification but for the identification of necessary information on disabilities, for example problems related to housing and economic circumstances (Z59), problems related to the social environment (Z60), problems related to the primary support group (Z63), problems related to life-management difficulty (Z73) and problems related to care provider dependency (Z74).

The ICIDH is considered the more useful tool in the near future. At present implementation of this classification scheme is problematic because of its complex structure. A network of institutions is currently studying the ICIDH to convert it into an measurement instrument which can be generally accepted.

To identify information on disabilities both the Z-code of the ICD and the ICIDH deliver relevant information. The underlying reasoning seems to be the same for the Z-code and the ICIDH. More study is needed to integrate the Z-code and the ICIDH codes. The question is not which classification scheme to choose but to select the disability items needed. These items should include at least the HFA-indicators on disabilities.

Besides the selection of items, the construction and evaluation of severity measurements should have high priority. Different severity scales are being used, hampering the comparison of data. In some scales severity is measured in terms of characteristics of diseases, while other scales are based on characteristics of disabilities. For the development and implementation of disability based scales, some evaluation is needed, for example by means of consultation meetings.

Selection of relevant items

The four areas, mentioned in box 1, cover the most basic information on disabilities. However, the meeting suggested that the topics included should be adapted.

The structure of the background variables is not quite logical and asks for some modification:

- demographic variables are: age, sex, urban/rural residence, marital status;
- socioeconomic variables are: educational attainment, economic activity, income;
- household variables refer to: household information, family composition.

More problems are expressed with the topics which describe the disability experience. The following transformation is suggested:

- kind and degree of disability (13+14)
- underlying impairments (10+14)
- underlying diseases (12)
- age of onset
- use of technical aids (15)
- use of services and treatment (16)
- addition of some problems from Z-list in ICD-10.

Sources of data on disability

In order to sustain the process of evaluating progress towards HFA, continuous data collection is indispensable. Continuous data collection forms a monitoring and surveillance system in that it reveals changes in time and international variations. In European countries, several sources of data on quantitative indicators exist. For the identification of information on disabilities three types of data sources were discussed (10).

1. Comprehensive administrative records already established for health or other purposes

These registration systems include administrative records and registration programmes. Administrative records which cover data on disability can be found in social security systems. First steps have been made to apply the ICIDH in the social security registration schemes. An overview of this kind of application in European countries can be expected ultimo 1990.

Registration programmes are used for various health conditions: for cancer, cardiovascular and other chronic diseases. Data on chronic conditions, however, only indirectly give information on disabilities, in the sense that some diagnoses result in more severe disabilities than other diagnoses.

2. Surveillance systems within the health services

To get a systematic overview of potential data sources, the health care system can be subdivided in three functional groups: medical care, rehabilitation and nursing care.

2.1 Medical care: general practitioners and hospitals

The main example of this type of registration is the "sentinel-physician" surveillance system applied in several countries. It involves a limited number of general practitioners who report on a list of carefully chosen topics. This system partly covers information on the incidence and the prevalence of selected chronic conditions and as a consequence gives only a limited picture of disabilities.

Hospital registration systems cover medical data on admissions and discharges and are as such a weak source for data on disabilities.

2.2 Rehabilitation

The ICIDH proves to be applied by workers in the field of rehabilitation in many countries (11). In most cases the ICIDH is used at the micro level (patient care). Some rehabilitation centres are developing a system to construct patient profiles in terms of disabilities. Only a few applications at a macro level are known. One of them is the United Nations World Programme of Action concerning Disabled Persons (mentioned on pp. 3-4).

2.3 Nursing care

Long-term care institutions can produce useful information on disabilities, especially on levels of dependency. Community-based care as well as institutional care are important data sources.

3. Community-based surveys

General information on health status indicators is obtained through specific health interview surveys or through regular broadly-based "microcensus" types of surveys with a health component (household surveys). These surveys contain various data on the HFA indicators of disability. Specific information on disabilities is provided by disability surveys, conducted in a limited number of European countries.

The sources of data on disabilities are summarized in Table 1.

Comparison of registration systems and surveys

The utility of data sources to monitor progress towards HFA indicators of disablement is determined by the completeness of information, the specificity of information, the coverage rate, the availability of additional information and the accessibility for analysis.

1. Completeness of information

Medical registration programmes cover many aspects of chronic conditions. Data on chronic conditions, however, are not sufficient for the assessment of trends in disability. In general, surveys are a more suitable instrument to collect information about disabilities; by means of surveys it is more difficult to collect information about impairments and diseases. The potential to build more "medical/objective" measurements into interviews by either using new measuring tools or by incorporating a nurse or physician examination into the interview has been recommended earlier (12). The ICIDH has the potential to provide a conceptual link between medical data and survey data. Improving application of the ICIDH as an instrument to measure health status is continuing (13).

Table 1. Sources of data on disabilities

Source of data	Data on disabilities
1. Administrative records	
- Registration programmes	Chronic conditions
- Social security systems	Links with ICIDH
2. Surveillance systems within the health services	
2.1 Medical care	
- General practices	Chronic conditions
- Hospitals	Medical data (admissions, discharges)
2.2 Rehabilitation	Links with ICIDH
2.3 Nursing care	
- Community-based care	level of dependency
- Institutional care	level of dependency
3. Community-based surveys	
- Health interview surveys	Several HFA indicators
- Household surveys with a health component	Several HFA indicators
- Disability surveys	A range of specific data

2. Specificity of information

The possibilities for the assessment of trends in disabilities are also dependent on the specificity of data. In medical registration systems more detailed information is available on the causes of disabilities (diseases and impairments). Surveys, on the other hand, have a higher potential to collect specific data on the disability status.

3. Coverage rate

Health care related registration systems as a rule cover only a selection of the population. On the basis of surveys and administrative records it is much easier to get a representative picture of disablements in the population.

4. Availability of additional information

The analysis of disability data requires additional information. Administrative records cover a range of data in their particular areas. In general, health care related registration systems concern only a few additional sociodemographic data (age and sex). Surveys are a much more flexible instrument to include various additional variables.

5. Accessibility for analysis

Privacy considerations determine to a great extent the accessibility of registrations for specific analysis. Registrations in health care related systems have their own purposes. In general, data from these registrations are much more difficult to obtain than data from administrative records and surveys.

The judgements on the utility of data sources are presented in Table 2.

Table 2. The utility of sources of data on disabilities

	Administrative records	Health care related systems	Community-based surveys
1. Completeness of information	+/-	+/-	+
2. Specificity of information	+/-	+/-	+/-
3. Coverage rate	+	-	+
4. Availability of additional information	+	-	+
5. Accessibility	+	-	+

This table provides the basis for the decision on which data sources the study on trends in disability should be concentrated. In the present situation, surveys seem the most feasible instrument for the assessment of disabilities, even though surveys involve lay perceptions. Recently the Netherlands Central Bureau of Statistics conducted a comparative study on questions concerning health for all indicators in health interview surveys (14). A more detailed follow-up of this study is recommended for specific

disability surveys as well as for other registration systems. The usefulness and availability will determine the selection of items. In this context, the work of Colvez (15) should be taken into account.

Recommendations

The creation of a database system requires definite agreements on information needs, which demands conceptual decisions as well as methodological decisions.

Conceptual decisions

A well defined conceptual scheme is needed for the implementation of data in daily practice by local, subnational and national bodies dealing with databases on disablements. These well defined conceptual schemes should be brought to the attention of international bodies for their consideration and eventual implementation. Unequivocal statements on the aspects of the disability status and background variables are required. For the assessment of trends in disabilities within the HFA monitoring process, the following variables are suggested (Table 3).

Table 3. Relevant variables for the assessment of trends
in disabilities for the HFA monitoring process

-
1. Demographic variables: age, sex, urban/rural, marital status.
 2. Socioeconomic variables: income, education, occupation.
 3. Household variables: family composition, household information.
 4. Aspects of the disability status:
 - (a) kind and degree of disability (ICIDH)
 - (b) underlying impairments (ICIDH)
 - (c) underlying diseases (ICD9/10)
 - (d) age at onset
 - (e) use of technical aids (ISO standard)
 - (f) use of services and treatment (ICPC)
 - (g) nonmedical problems and level of dependency (Z list ICD-10).
-

Methodological decisions

Indicators of disability need to be expressed in a standardized way. Without standardization the assessment of longitudinal trends and international comparisons are virtually impossible. The data sources and methods of data collection should be studied further. It is recommended to confine this study to a limited number of European countries, namely to those countries which conduct large-scale disability surveys: the Netherlands,

Norway, Spain and the United Kingdom. The indicator and instruments used in the disability surveys in these countries will be reviewed and furthermore other data sources on disablements in these countries will be analysed. On the basis of an integrated framework of data (sources) the possibilities of the implementation of a database system in central and eastern Europe will be studied. This region has a high priority at the moment in WHO policy. For this part of the study, it is proposed to incorporate the following countries: Czechoslovakia, Hungary, Poland and the USSR. It is suggested that this study be conducted by one or two consultants and by organizing some international expert meetings. In this context, the work of Colvez and UNSO/DISTAT serves as an important source of information. Financial resources are still to be found. Ms de Kleijn de Vrankrijker is willing to consider the possibilities of making a financial contribution. Also the WHO Regional Office for Europe is prepared to look for sponsors.

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Annex 1

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