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Collecting data on disability in EU general population surveys

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Session 6: Choosing a data collection mechanism: census or survey

Collecting data on disability in EU general population surveys

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[1] The views expressed in this paper are those of the author and do not necessarily reflect the policies or position of Eurostat

1. Disability in EU national population surveys

With respect to choosing a data collection mechanism for the measurement of disability in the European Union[2], the use of the census is limited. To our knowledge there were no (screening-) questions on disability in the 2000 Censuses of population and housing in the EU. It is noted that the United Nations and Eurostat recommendations for censuses in the ECE region, which includes the EU, do not contain a health or disability related item (ref. 1).

Typical 'disability surveys' have been conducted in a number of EU countries. Eurostat has summarized the information in these surveys in two publications, of which the most recent was published in 1995 (ref. 2). When looking at only the past 6-7 years, we find disability surveys in the EU in Portugal 1994, Austria 1995, United Kingdom 1996, France 1999, Spain 1999[3].

Practically all Member States of the European Union conduct regular 'Health Interview Surveys' (HIS) or other surveys with a significant health component. Some are yearly, others less frequent; practically all contain questions on disability. In recent years, overviews of methods and contents (questions) of these surveys have been produced, among others at the request of and supported by the Eurostat Task Force on 'Health and health related survey data'.
The latest, and for the first time 'electronic', overview of methods and contents of these surveys can be found in the so called 'HIS/HES database' (ref. 3). This database -using Microsoft Access- was produced by Statistics Netherlands and KTL (National Public Health Institute, Finland) under contract for the European Commission - Health Monitoring programme. The current version of the database is a product of the first phase of this project; in the recently started second phase the database will be further developed and updated.
The database can be used for computer facilitated comparison and evaluation of methods and content (questions) in national HIS and other surveys with a significant health component in the EU. Earlier studies on these comparisons and evaluations had to do a lot of 'manual browsing' in order to get insight in the material.

As can be seen from the HIS/HES database and several earlier studies, when comparing the measurement of long term physical disability between the EU Member States, it appears that most surveys use nationally amended (!) versions of the 'OECD long term disability indicator' (ref. 4) or the 'WHO-Euro recommended instrument for long term disability'(ref. 5). Recently, in another Health Monitoring Project (ref. 6), these amendments were evaluated. Among other things it was concluded that countries were

[2] The 15 Member States of the European Union:
B-Belgium, DK-Denmark, D-Germany, EL-Greece, E-Spain, F-France, IRL-Ireland, I-Italy, L-Luxembourg, NL-the Netherlands, A-Austria, P-Portugal, FIN-Finland, S-Sweden, UK-United Kingdom.
[3] Source: HIS/HES database, see ref. 3.

not sufficiently (made) aware of the implications with respect to international comparability when they amended the instruments - through selection of items, change of question wording or response categories. It was also concluded that the two recommended instruments mentioned above, ‘which both currently mix functional limitations and activity restrictions’ should be updated. With respect to the area of functional limitation / activity restrictions proposals were made for a general question about activity restrictions, a set of specific questions on physical and sensory functional limitations, a set of specific questions on personal care activities. In the second phase of the project proposals will be made for a set of specific questions on cognitive functional limitations, a set of specific questions on household activities, a set of specific questions on other activities of daily living.

In 1999/2000 Eurostat, with the support of the Task Force ‘Health and health related survey data’, has collected from the EU Member States HIS data on 12 topics, including data on long term disability by type, age, sex, education and economic activity. Data on walking, hearing, seeing, stairs, retrieval, speaking, ADL were received from 6-9 countries (number of countries delivering data ranges from 6-9 per item). The analysis of these data is still in progress. It will be taken into account that, when analysing disability data from surveys in different countries – using instruments similar but not identical to the OECD and WHO-Euro recommended instruments - direct comparisons can not be made in many cases. Sometimes simple forms of ‘ex post harmonisation’ on the question level - for instance combining response categories- may improve comparability on this level; sometimes the construction of an ‘index/indicator’ (combination of similar sets of items in different countries) may result in a variable sufficiently comparable for analysis of correlation of disability with other variables, as demonstrated in earlier studies (ref. 7)

2. Disability in European Community Household Panel

Another experience with respect to the collection of disability data through general population surveys in the EU to be reported here is the collection of such data through the European Community Household Panel (ECHP). The study of (changes in) ‘income’ was the initial drive for the survey, but from the beginning the scope was widened to other social fields. The ECHP is a survey co-ordinated by Eurostat; it is based on a standardised questionnaire that involves annual interviewing of a representative panel of households and individuals in each country, covering a wide range of topics: income, **health**, education, housing, demographics and employment characteristic, etc. The survey is planned for a total duration of 9 years. The first wave of the ECHP was conducted in 1994 in the then 12 EU Member States; it was based on a sample of some 60 500 private households (about 130 000 adults aged 16 years and over). Since then, new Member States Austria and Finland have joined the project. ECHP data are collected by 'National Data Collection Units' - 'NDUs', either National Statistical Institutes (NSIs) or research centres, depending on the country; see ref. 8 for more details.

Three characteristics make the ECHP a unique source of information. These are (i) its multi-dimensional coverage of a range of topics simultaneously; (ii) a standardised methodology and procedures yielding comparable information across countries; and (iii) a longitudinal or panel design in which information on the same set of households and persons is gathered to study changes over time at the micro level.

In a multi purpose survey such as the ECHP there is limited space for a health module. The current module contains questions on health status, including a global question on disability, and questions on health determinants and the use of medical services. The health status questions are printed in annex 1. The questions of interest related to measurement of disability are:

Q158: Do you have any chronic physical or mental health problem, illness or disability?
if Yes Þ *Q 159*

Q159: Are you hampered in your daily activities by this chronic physical or mental health problem, illness or disability?
Yes, severely / Yes, to some extent / No

Recently the data from the 1996 wave of the ECHP were used for an analysis of the social participation of persons reporting disability, as compared to the social participation of persons not reporting disability (publication forthcoming). Some key results will be presented at the seminar.

A 'future experience' to be reported here: the successor of the ECHP, a yearly 'Survey on Income and Living Conditions' (SILC), will start in 2003 according to Eurostat and Member States current plans. Only an absolute minimum set of health questions, probably the recently proposed 'Minimum European Health Module'[4] will be incorporated in the yearly survey. In addition a possibility for different ad hoc modules, for instance on health, is foreseen. The proposed 'Minimum European Health Module' is printed in annex 2.

3. Disability in European Labour Force Survey (ad hoc module)

In 2002 the European Labour Force Survey (LFS) will contain an ad hoc module on the employment of disabled people. According to the Regulation on the LFS (see below) there is a yearly possibility for an ad hoc module, containing a maximum of 11 variables. The 2002 disability module is to fulfil the need for a comprehensive and comparable dataset on the labour market situation of people with disabilities, as referred to in the Council Resolution of 17 June 1999 on equal opportunities for people with disabilities. The rationale behind the inclusion of an ad hoc module on disability in the LFS is to meet the above mentioned policy needs by using the most appropriate and cost effective way.

[4] As proposed by the Health Monitoring project on selection of a coherent set if health indicators

The content of the LFS, including the ad hoc modules, is determined by the Statistical Office of the European Union (Eurostat), together with the national experts of the Member States. An agreed coding scheme is then used by the Member States to transmit the data. A detailed presentation of the information provided by the regular survey is given in Annex IV of Commission Regulation (EC) No 1571/98, which lays down the rules for applying Council Regulation No 577/98 on the organisation of a labour force sample survey in the Community.
The National Statistical Institutes are responsible for selecting the sample, preparing the questionnaires, conducting the direct interviews with households and forwarding the results to Eurostat in accordance with the standard coding scheme. Eurostat is responsible for processing and disseminating the information forwarded by the national institutes. The sampling methods, adjustment procedures and definitions and the standardised coding system are described in a Eurostat publication (ref. 9)
The survey is intended to cover the whole of the resident population, i.e. all persons whose usual place of residence is in the territory of the 15 Member States of the European Union. For technical and methodological reasons, however, it is not possible in all countries to include the population living in collective households, i.e. persons living in residential homes, boarding houses, hospitals, religious institutions, workers' hostels, etc. To harmonise the scope of the survey, therefore, the Community results are compiled on the basis of the population of private households only. This comprises all persons living in the households surveyed during the reference week. This definition also includes persons absent from the household for short periods (but having retained a link with the private household) owing to studies, holidays, illness, business trips etc.

The LFS 2002 ad hoc module on the employment of disabled people.

A full description of the module, including description of each variable, its coding, rationale and applicability, along with the interviewing instructions can be found in the extensive 'explanatory notes' document (ref. 10, available at request). The constraint of a maximum of eleven variables means that the chosen topics must be of a general nature to cover the large range of working practices, types of disability, and person/environment interactions. The (global) content and structure of the module is shown in the flow chart in Annex 3. The formal description of the variables and the suggested questionnaire are available at request.

4. Summary; concluding remarks

With respect to collecting data on disability in EU national population surveys we have a reasonable complete and up to date overview in the 'HIS/HES database'; at least in the coming two years this database will be kept up to date. When looking at the past 6-7 years we find in only 5 EU countries the typical disability survey which gives in-depth information on the nature, severity, cause, duration and other aspects of disability. In practically all countries we find (regular) Health interview surveys, or other surveys with a

significant health component, containing questions on disability by nature and severity. Although more limited with respect to the scope of information on disability, these surveys allow for analysis of disability in relation to other health and health related dimensions. As a rule, the disability questions in these surveys are similar, but not identical to the existing recommended instruments for measuring long term disability (ref. 4 and 5). Efforts to update these instruments are ongoing in Europe (ref. 6).

The international comparability of disability data coming from national surveys in the EU is limited. Ex-post harmonisation may improve the comparability in some cases, but the longer-term solution should be that Member States use recommended instruments without unnecessary amendments. Once this ‘minimum condition’ is fulfilled, other barriers to comparability may become more apparent and require further research, such as differences in language and (survey-) culture - for instance different attitudes towards reporting disability.

In the European Community Household Panel, co-ordinated by Eurostat, a global question on disability was included in all waves. Recently the 1996 data were used for an analysis of the social participation of persons reporting disability, as compared to persons not reporting disability. In 2002 the European Labour Force Survey will contain an ad hoc module on the employment of disabled people. The module is to fulfil the need for a comprehensive and comparable dataset on the labour market situation of people with disabilities in the EU Member States (ref. 10).

For different purposes and types of surveys ‘disability modules’ varying with respect to scope and length are needed. It is Eurostat’s intention to provide EU Member States with recommended instruments for the various types of modules in national surveys. These may be identical to already existing recommended instruments, or to instruments being developed at the moment. If needed for a specific type of module, efforts will be made or stimulated for the development of an instrument. With respect to the development of questions for the typical disability surveys, a recent draft report regarding ‘indicators on integration of disabled persons into social life’ (ref. 11) could serve as a useful checklist.

Annex 1

Health status questions[5] in the European Community Household Panel

P053390 Q157: How is your health in general?

	Answer	Code	
P053390	Very good	1	
	Good	2	
	Fair	3	
	Bad	4	
	Very bad	5	
	Missing	9	

P053400 Q158: Do you have any chronic physical or mental health problem, illness or disability?

	Answer	Code	Go to
P053400	Yes	1	⇒P053410
	No	2	⇒P053420
	Missing	9	⇒P053420

P053410 Q159: Are you hampered in your daily activities by this physical or mental health problem, illness or disability?

	Answer	Code
P053410	Yes, severely	1
	Yes, to some extent	2
	No	3
	Missing	9

Q160: Please think about the two weeks ending yesterday: Have you had to cut down on any on the things you usually do about the house, at work or in your free time ...

P053420 - because of illness or injury?

	Answer	Code
P053420	Yes	1
	No	2
	Missing	9

P053430 - because of an emotional or mental health problem?

	Answer	Code
P053430	Yes	1
	No	2
	Missing	9

[5]: The ECHP questions on the use of medical services and on determinants/lifestyle are not printed here. These are available at request with the author.

Annex 2

Minimum European Health Module[6]

1. How is your health in general? Very good / good / fair / bad / very bad

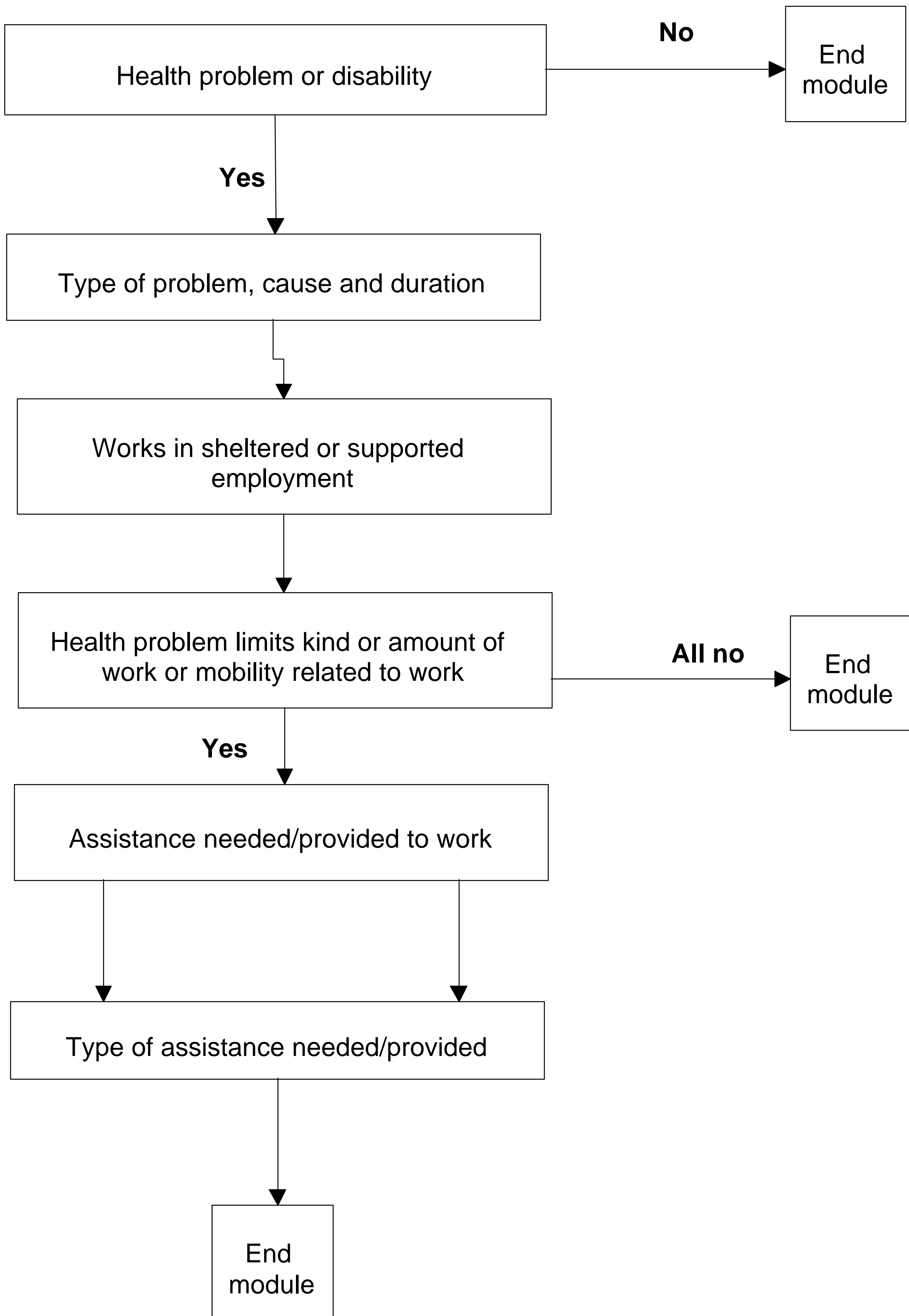
2. Do you have any long-standing[7] illness or health problem? .Yes/no

3. For the past 6 months or more, have you been limited in activities people usually do because of a health problem? Yes, strongly limited / Yes, limited / No, not limited

[6] Proposed by the Health Monitoring project on selection of a coherent set if health indicators

[7] For those countries that use 'chronic' as a more general term than 'long-standing', the term 'chronic' is recommended

Annex 3 Content and structure of LFS 2002 ad hoc module



References

1. United Nations and Eurostat; Recommendations for the 2000 censuses of population and housing in the ECE region; New York and Geneva, 1998

2. Eurostat; Disabled persons, statistical data - second edition; Luxembourg, 1995

3. C. Hupkens and H. Swinkels, Statistics Netherlands; Health interview surveys in the EU: overview of methods and contents; Heerlen-NL, 2001. (Report on the Health Monitoring project 'Health surveys in the EU: HIS and HIS/HES evaluations and models). The 'HES-part' is reported in: P. Koponen and A. Aromaa, National Public Health Institute (KTL) Finland; Health examination Surveys (HES), review of literature and inventory of surveys in the EU/EFTA Member States; Helsinki 2001

4. J.R. McWhinnie, Measuring disability; Organisation for Economic Co-operation and Development, Paris 1982 (OECD Social Indicator Development Programme, special studies, No 5)

5. Health Interview Surveys - Towards international harmonization of methods and instruments; edited by A. de Bruin, H.S.J. Picavet (Statistics Netherlands) and A. Nossikov (WHO Regional Office for Europe); WHO Regional Publications, European Series, No 58; 1996.

6. Selection of a Coherent Set of Health Indicators - A First Step Towards a User's Guide to Health Expectancies for the European Union; edited by J-M Robine, C. Jagger and V. Egidi; Euro-REVES, Montpellier, 2000. (summary report on Health Monitoring Project)

7. A. E. Kunst, V. Bos, J.P. Mackenbach, EU Working Group on Socio-economic Inequalities in Health; Monitoring socio-economic inequalities in health in the European Union: guidelines and illustrations; Department of Public health, Erasmus University, Rotterdam, 2000 (report on Health Monitoring Project)

8. The European Community Household Panel (ECHP): Volume 1 – 'Survey methodology and Implementation' and 'The European Community Household Panel (ECHP): Volume 1 - Survey questionnaires: Waves 1-3' - Theme 3, Series E, Eurostat, Luxembourg, 1996

9. Labour Force Survey - Methods and Definitions, 1998 edition; Theme 3, Population and Social Conditions, Eurostat, Luxembourg 1999

10. H. Meltzer, National Statistics Social Survey Division, London; Proposal for the 2002 LFS ad hoc module on disability; Luxembourg 2001.

11. G. Boccuzzo, V. Buratta, F. Deriu and others, National Institute of Statistics – Italy; 'Indicators on integration of disabled persons into social life', executive summary; Luxembourg 2001.