



**PROJECT "INDICATORS ON INTEGRATION OF
DISABLED PERSONS INTO SOCIAL LIFE"**

**FINAL REPORT
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I. FOREWORD

I.a The goals of the project

Persons living with disabilities constitute a significant proportion of the European Community's population (estimated at around one tenth of the total population¹): a group of citizens who every day "face to a wide range of obstacles which prevent them from achieving equal opportunities"², independence and a full integration into social life. Considering that the respect of human rights is a fundamental value shared by all Member States³ (MS), the integration of persons with disabilities should represent a main goal that all the MS would have to reach through a policy action aimed to:

- eliminate all physical and psychological barriers;
- foster the access to mainstream education and to a good quality training;
- support the inclusion in the labour market;
- stimulate the provision of a support in order to facilitate participation.

Integration is now considered as a key issue to focus on, in order to improve the inclusion of people with disabilities in active society.

As a consequence, the ex DGV of the European Commission assigned to ISTAT (Italian National Institute of Statistics) the project called "Indicators on Integration of Disabled Persons into Social Life". At the current time, this Project represents one of the actions started by the European Commission to this aim and its main goal is to identify a small set of indicators suitable for monitoring the efficacy of integration policies directed to persons with disabilities.

This set of indicators should constitute a tool for informing the policy-makers on the status of the integration of disabled persons into economic and social life as well as for allowing them to plan new intervention strategies. To serve this function, however, it is essential that the indicators correlate with the internationally accepted definition of 'disability' for comparability of data. In addition, the indicators must provide policy-makers with the basis for assessing the extent of participation and inclusion, otherwise it would not be possible to identify either problems of inclusion, or to track improvements in inclusion brought about by interventions. For both terminological comparability and assessment, it is recognized that these indicators should be based on the domains found in the World Health Organization's International Classification of Functioning, Disability and Health (ICF).

This final report is the result of a wide interaction with several experts: two progress reports were prepared and presented in occasion of two different meetings held in Brussels, the first one in April 2000 and the second one in October 2000. During these two meetings, all the member of the expert group offered many useful suggestions.

In April 2001, the executive summary was distributed and circulated among the members of the task force "Health and health related survey data" for a wider consensus on the structure and on the report contents. Moreover, useful comments from WHO and OCSE experts have been considered. Comments received from this circulation round have been included in this final report.

The project co-ordinator wishes to thank all persons who contributed to this report, especially the experts and project leaders on statistics on disability.

I.b The main normative sources

The identification of the indicators suitable for monitoring social integration of disabled persons into social life has started from some main International and European normative sources.

¹ Commission of the European Communities, Communication to the Council, the European Parliament, the social and economic Committee, the Regional Committee on "Towards a barrier free Europe for People with Disabilities", Brussels, pg.5, May 12nd, 2000 EDF, "Accessible Access to Urban Areas, pg.6, June 2000.

² Resolution of the Council on "Equality of opportunity for people with disabilities", 20 December 1996.

³ Treaty of the European Union, Article F.2

First of all, the Resolution on Standard Rules⁴ for the Equalisation of Opportunities for Persons with Disabilities, that was adopted by the United Nations General Assembly in 1993, has been considered. This document covers all the aspects of disabled person's life and it is structured into 22 rules, classified in 4 main thematic areas:

- a) Pre-conditions for a full participation
- b) Fields to be addressed for reaching a full participation
- c) Positive actions to be taken
- d) Follow-up mechanism

The Standard Rules adopts the conceptual model of disability found in the ICIDH 1980 version, noting that the ICIDH "has been extensively used in areas such as rehabilitation, education, statistics, policy, legislation, demography, sociology, economics and anthropology." Specifically, the Standard Rules adopts the distinction between functional limitations resulting from a health condition that are intrinsic to the person, and loss or limitation of opportunities to take part in the life of the community on an equal level with others as a result of an interaction between the functional limitations and the person's physical and social environment. The ICF has further clarified and operationalized this distinction (now expressed in terms of the difference between Impairments and Activity Limitations on the one hand, and Participation Restrictions on the other). The ICF in addition makes the distinction between the capacity limitations of a person that are attributes of the health state and performance of a person which is what happens in the person's real life or actual environment. As a result, every principle and recommendation in the Standard Rules incorporates the model of disability expressed in the ICF. In particular, the key notions of 'equalization of opportunity' and 'inclusion' are based on the notion of Participation and performance found in the ICF.

Afterwards, the White Paper entitled "European Social Policy - A Way Forward for the Union" published by the European Commission, on 27th July 1994, has been considered. By this document the Commission has indicated its purpose to take up the principles of the Standard Rules. Nevertheless many problems continue to account for the under-participation of people with disabilities in our society. For this reason, an interesting report entitled "Invisible Citizens" was published by some NGOs during the European Day of Disabled People in December 1995, referring on difficulties and adverse situations that people with disabilities experience within the Union.

Another basic document which was referred to, is the Communication of the European Commission on "Equal opportunities for disabled people", dated July 1996, in which is specified the meaning of the *mainstreaming* concept and all the MS are invited to study specific measures and actions, within the general policies, in order to offer equal opportunities and to foster an equal participation and both an economic and social integration of disabled persons. On the basis of this Communication, the Resolution of the Council of the European Union on "Equal opportunities for Disabled People" was adopted on 20th December 1996. By this Resolution, all the MS have been invited to develop, to foster and to enhance measures for a full participation of disabled persons into social life.

During the same year the European Parliament has adopted a Resolution on "Disabled People Rights" (31st December 1996). By this Resolution, the Commission has been invited on funding initiatives of organizations as the European Disability Forum. Moreover, some issues such as the participation of disabled persons in the decision-making processes, the access to adequate information, the development of adaptive technologies, and the implementation of active and passive measures aimed at the participation of disabled persons into political activities, have been reaffirmed.

⁴ United Nations, Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993

II REPORT STRUCTURE

The logical structure of the report is divided in four main areas:

1. *Core indicators*, concerning a general description of the phenomenon so that the policy-makers and the researchers are given the necessary information to have a general view of the disability issue;
2. *Preconditions*, that is the fundamental prerequisites for the achievement of social integration. In this area the following items are included: accessibility, health and health service, and social protection. No social integration is measured in this area, but the system of basic conditions for the realization of social integration
3. *Target areas*, that is a set of indicators addressed to monitor the results of policy choices and more specifically related to integration topic, with regard to some specific intervention areas such as education, employment and social participation.
4. *Other relevant aspects* of the phenomenon: the role of families, disabled persons in institutions, individual satisfaction, disabled and violence, disabled and communication technologies.

Logical plan of the indicator's set

Core indicators	Preconditions			Target areas			Other relevant aspects
	Accessibility	Health and health service	Social Protection	Education and school integration	Employment and Training	Social Participation	
Disability Prevalence	Architectural barriers	Health status	Expenditure	Education Levels	Unemployment	Cultural integration	Role of families
Family context	Mobility	Health expenditure	Benefits	Participation Measures	Disabled Gap	Relationships	Disabled in institutions
Educational Level	Communication	Prevention		Special Education	Financial Resources	Sport	Satisfaction
Professional Condition	Information and Communication			Integration in normal schools	Training	Political life and citizenship	Disabled and violence
Economic Condition				Human resources		Religion and spirituality	Disabled and communication technologies

III. CRITERIA FOR THE IDENTIFICATION OF A LIMITED NUMBER OF INDICATORS

III.a Criteria for the selection of indicators

At first a wide number of indicators had been identified, but afterwards it became necessary to define the criteria for choosing a limited and more specific set of indicators.

The first guideline was the *policy relevance*: it is met when the indicator fits in monitoring the European policies on disability; when it provides information about what is needed starting from the point of view of policies; when it highlights current and potential problems related to integration of persons with disabilities in each sphere of the social life and "links to topics that policy can influence".⁵ To this aim, an accurate analysis of the European guidelines has been developed, based

⁵ Working Committee on Quality Indicators, "Indicators and benchmarks of Quality of school education", First progress report, June 1999.

not only on the policies for disabled, but also on the general policies related to specific thematic areas, like employment, education, social protection, and so on.

A problem subsequent to this selection approach is that the data source can be absent or can present some problems for the calculation of the indicator (small sample size, comparison between member states, ...). On the other hand, this is the price to pay for choosing a top-down approach. At the same time this approach gives to member states the indication for developing new data sources or improve the existing ones.

Also in this field the well-known problems of comparability are present: within the European Union there are many different systems, as well as different priorities on policies on disability, and it could appear really difficult to fix a set of indicators comparable among all these Countries. An effort should be done taking into account the national priorities as well as the European Agenda on disability. Central to this project is the need to correlate all policy relevant data by means of common classifications, that provide the international and interlinguistic common language.

III.b Main characteristics of each indicator

Within each working area indicators are described by a schedule including the following characteristics (see V):

- 1) Description
- 2) Stratification levels
- 3) Further specific indicators
- 4) Rationale
- 5) Data source
- 6) Computability and comparability
- 7) Updating frequency

The description of the indicator shows how to calculate it and the stratification level includes the list of the variables involved in the process of stratification. Under the term specific indicators are indicated more specific representations of the same indicator: e.g. standardized or specific rates. The rationale represents the reason the indicator is based on, and the logical process that has conducted to its choice and identification.

The definition of the data sources gives important information on if, how and where data are collected. Computability and comparability concerns two basic aspects of this topic: in fact computability is not sufficient for the validation of an indicator at a European level. It is necessary that an indicator is comparable with the corresponding in other MS. At the present time this is not an easy work, but efforts have to be done in order to improve the level of comparison of data among the countries of the EU. Finally, it is worthwhile to indicate the updating frequency of each indicator, specifying if it is a short-term, medium-term or long-term indicator.

IV. GRID OF ALL THE INDICATORS IDENTIFIED WITHIN EACH AREA

The following pages include a summarising grid of all the indicators identified for the description of the general context, of the preconditions and of the target areas. Within each area, it is indicated:

1. the subdomain and the concern corresponding to each indicator;
2. the definition of the chosen indicators;
3. the list of further specific indicators;
4. the corresponding stratification levels;
5. the data sources.

This grid is designed for being user friendly and a useful tool both for researchers and for policy-makers.

The grid is followed by a section including a more detailed description of each indicator of the list.

IV.a General overview of the selected indicators

CORE	PRECONDITIONS			TARGET AREAS		
	ACCESSIBILITY	HEALTH AND HEALTH SERVICE	SOCIAL PROTECTION	EDUCATION AND SCHOOL INTEGRATION	EMPLOYMENT AND TRAINING	SOCIAL PARTICIPATION
Disability crude rate per 1.000 inhabs.	Percentage of accessible public places	Disability Free Life Expectancy at birth	Percentage of social expenditure in “Disability function” on GDP	Standardised literacy rate of disabled aged 15 and over	Unemployment rate	Standardised percentage of participation in social, cultural and political activities
Percentage of disabled persons married	Percentage of expenditure for adapting public places on GDP	Standardised percentage of disabled persons with two or more chronic disease	Percentage of social expenditure for disability pension on the total of pension expenditure	Proportion of students in cross-national Category A ⁶ as a percentage of all students in primary and lower secondary education	Mean length of the unemployment	Standardised percentage of participation in social relations
Percentage of disabled persons living alone	Percentage of accessible public transports	Rate of hospitalisation	Ratio between benefit in kind and cash benefit	Number of special schools relative to total school population	Disability pay gap	Standardised percentage of participation in sportive activities
Percentage of households with almost 1 disabled person living therein	Standardised percentage of disabled persons having driving licence	Proportion of health expenditure for disabled persons as part of the total health expenditure		Proportion of students in cross-national category A integrated in regular classes.	Ratio of active labour market expenditure for the disabled	Standardised percentage of participation in the vote
Standardised percentage of disabled persons with a high level of education	Percentage of persons with mobility assistive needs receiving suitable assistance	Percentage of the total expense for prevention and public health on the total of the health expenditure		Disabled students/Support staff ratio in special schools	Participation index	Standardised percentage of disabled persons attending religious services and events
Total employment rate	Percentage of persons with communication assistive needs receiving suitable assistance			Attendance in colleges and universities		
Rate of disabled persons under poverty line	Percentage of adapted web sites					

⁶ See V.e

IV.b Core indicators

DOMAIN: CORE INDICATORS		Overview: Core indicators offer a wide and general description of the phenomenon and they constitute for the researcher an important tool for the comprehension of the disability context.			
SUBDOMAIN	CONCERN	INDICATOR	SPECIFIC INDICATORS	Stratification levels recommended	DATA SOURCES
Disability Prevalence	Disability prevalence	Disability crude rate per 1.000 inhabs.	1) Standardised rate (European Population)	1) Gender 2) Age class 3) Type of disability 4) Region of residence	Basically the HIS
Family context	Familiar integration	Percentage of disabled persons married	1) Same indicator for non disabled. 2) Ratio between the indicators calculated for disabled and non disabled	1) Gender 2) Age class	Basically the HIS
		Percentage of disabled persons living alone	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	1) Gender 2) Age class	Basically the HIS
	Impact of disability on households	Percentage of households with almost 1 disabled person living therein		1) Type of household	Basically the HIS
Educational Level	Measure of differences in access to different educational levels	Standardised percentage of disabled persons with a high level of education (secondary school and more)	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	Gender	Basically the HIS
Professional Condition	Measure of differences in access to labour market	Total employment rate	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	1) Gender 2) Age 3) Sector activities	LFS and 2002 ad hoc module on disability, HIS or ECHP
Economic Condition	Analysing economic and social condition of disabled persons.	Rate of disabled persons under poverty line	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	1) Gender 2) Age 2) Type of household	ECHP

IV.c Indicators of accessibility

DOMAIN: ACCESSIBILITY		Overview: Accessibility represent a fundamental right to create a precondition to a full participation and integration in social life			
SUBDOMAIN	CONCERN	INDICATOR	SPECIFIC INDICATORS	Stratification levels recommended	DATA SOURCES
Architectural Barriers	Need of disabled persons to have physical environment accessible	Percentage of accessible public places (schools, workplaces, cinemas)		Type of public place	Different information is available at National level, depending on the type of place (see Vb)
	Monitoring expenditure for disabled persons to grant environmental accessibility	Percentage of expenditure for adapting public places (schools, workplaces..) on GDP		Type of public place	National Accounts if available
Mobility	Offer of accessible public transport means	Percentage of accessible public transports (trains, bus...)		Type of public transport	At the current time no data sources are available
	Driving independence of disabled persons	Standardised percentage of disabled persons having driving licence	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	1) Gender	Administrative data sources (e.g. the Ministry of Transport)
	Moving around using equipment	Percentage of persons with mobility assistive needs receiving suitable assistance		Gender and age	LFS with the 2002 ad-hoc module on disability (for those working)
Communication	Conversation and use of communication devices and techniques	Percentage of persons with communication assistive needs receiving suitable assistance		Gender and age	LFS with the 2002 ad-hoc module on disability (for those working)
Information and Communication	Access to information and communication by disabled persons.	Percentage of adapted web sites			See V.b

IV.d Indicators of health and health service

DOMAIN: HEALTH AND HEALTH SERVICE		Overview: Differences in health status and in need of assistance between disabled and non disabled persons are a fundamental tool. It requires attention from the health services. A good health assistance is crucial in order to fill the disadvantage of disabled persons			
SUBDOMAIN	CONCERN	INDICATOR	Specific indicators	Stratification levels recommended	DATA SOURCES
Health status	Life expectancy	Disability Free Life Expectancy at birth	Same indicator for the following ages: 15, 45, 65, 75.	Gender	Abridged life table and HIS (for the ages 15 and over). At birth an estimate of disability prevalence is necessary
	Chronic disease	Standardised percentage of disabled persons with two or more chronic disease	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	Gender	HIS
	Need of health assistance	Rate of hospitalisation	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	1) Gender and age class	HIS
Health expenditure	Health expenditure for disabled persons is adequate	Proportion of health expenditure for disabled persons as part of the total health expenditure		1) Expense item (e.g. prosthesis, ...) 2) Region	No direct source
Prevention	Health expenditure for prevention is adequate	Percentage of the total expense for prevention and public health on the total of the health expenditure		1) Expense item (e.g. prosthesis, ...) 2) Region	OECD Health data

IV.e Indicators of social protection

DOMAIN: SOCIAL PROTECTION		Overview: Social Protection is a key issue of modern Welfare State, to meet basic needs as minimum income, remunerated job, education and social integration in all activities of social life.			
SUBDOMAIN	CONCERN	INDICATOR	Specific indicators	Stratification levels recommended	DATA SOURCES
Expenditure	Measuring the national effort of Member States in Social Protection addressed to disabled persons	Percentage of social expenditure in “Disability function” on GDP			European System of Integrated Social Protection Statistics
	Monitoring pension schemes related to disabled persons.	Percentage of social expenditure for disability pension on the total of pension expenditure			European System of Integrated Social Protection Statistics
Benefits	Distribution between services and monetary benefits.	Ratio between benefit in kind (services) and cash benefit (monetary benefits)			European System of Integrated Social Protection Statistics

IV.f Indicators of education and school integration

DOMAIN: EDUCATION AND SCHOOL INTEGRATION		Overview: Ensuring the actual right to study and training is a factor affecting the world of the disabled, as long as it is an essential condition for their full integration in social life and in the labour market. Integration of persons with special education needs is a process by which a student is given the opportunity to develop and improve its education towards his/her economic and social autonomy.			
SUBDOMAIN	CONCERN	INDICATOR	Specific indicators	Stratification levels recommended	DATA SOURCES
Education Levels	Literacy level	Standardised literacy rate of disabled aged 15 and over	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	Gender	HIS
Participation Measures	Enrolment measure of disabled students within regular and mainstream schools	Proportion of students in cross-national Category A ⁷ as a percentage of all students in primary and lower secondary education	Same indicator for Cross-national categories B and C of students with special needs	Gender	OECD data collection linked to UOE on special needs education
Special Education	Measure of the amount of segregated provision in the form of special schools	Number of special schools relative to total school population	Average size of special school	Type of school (public/private)	OECD data collection linked to UOE on special needs education
Integration in normal schools	Extent to which disabled pupils and students are educated with their peers	Proportion of students in cross-national category A integrated in regular classes.	Same indicator for Cross-national categories B and C of students with special needs	Gender	OECD data collection linked to UOE on special needs education
Human resource	Support staff personnel involved into education of students with special needs.	Disabled students/Support staff (teacher) ratio in special schools	Same indicator for special classes in regular schools	1) type of school (public - private)	OECD data collection linked to UOE on special needs education
Higher education	Participation of disabled in higher education	Attendance rate in colleges and universities	Same indicator for non-disabled	Gender	University statistics or population surveys

⁷ See V.e

IV.g Indicators of employment and training

DOMAIN: EMPLOYMENT AND TRAINING		Overview: Gaining a job is a fundamental precondition for: reaching economic independence and consequently improving self-sufficiency; becoming integrated in the society, through improving the self esteem.			
SUBDOMAIN	CONCERN	INDICATOR	Specific indicators	Stratification levels recommended	DATA SOURCES
Unemployment	Exclusion from labour market	Unemployment rate	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled 3) Long-term unemployment rate	1) Gender and age class	LFS with 2002 ad-hoc module on disability or ECHP or NHIS
	Critical exclusion from labour market		Mean length of the unemployment	1) Gender and age class 2) Type of disability	LFS with 2002 ad-hoc module on disability or ECHP
Disabled Gap	Equal opportunities between disabled and non disabled persons	Disability pay gap		1) Gender 2) Type of disability 3) Activity sector	ECHP
Financial Resources	Active measures for employability	Ratio of active labour market expenditure for the disabled			OECD database on labour market programmes
Training	Long-term training participation	Participation index		1) Gender and age class 2) Type of disability	LFS with 2002 ad-hoc module on disability

IV.h Indicators of social participation

DOMAIN: SOCIAL PARTICIPATION		Overview: This topic concerns both the effectiveness of the policies implemented, in order to guarantee the equality of the opportunities of the various spheres of social life and the full exercise of citizens' rights, and the extent of social cohesion, through the monitoring of the relations that exist among the members of society itself, referring in particular to the presence/absence of phenomena of discrimination and social exclusion.			
SUBDOMAIN	CONCERN	INDICATOR	Specific indicators	Stratification levels recommended	DATA SOURCES
Cultural integration	Extent of the participation of disabled persons to integrated community activities	Standardised percentage of participation in social, cultural and political activities	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	Gender	ECHP
Relationships	Extent of persons with disabilities gain and enjoy friendships and relationships	Standardised percentage of participation in social relations	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	Gender	ECHP
Sport	Involvement of disabled persons in physical activities	Standardised percentage of participation in sportive activities	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	Gender	HIS
Political life and citizenship	Exercise the right of vote	Standardised percentage of participation in the vote	1) Same indicator for non disabled 2) Ratio between the indicators calculated for disabled and non disabled	Gender	None
Religion and spirituality	Exercise the right of worship	Standardised percentage of disabled persons attending religious services and events	1) Same indicator for non disabled	Gender	None

V. DETAILED DESCRIPTION OF THE INDICATORS

V.a Core Indicators

Prevalence data constitute the first information that a researcher needs before starting the study of a new phenomenon. Moreover, the knowledge of some basic socio-demographic characteristics of the disabled persons, such as the educational level, the marital status, the professional condition, is fundamental in order to have a wider framework of the disability phenomenon. Another important aspect to consider concerns the influence that the presence of a disabled person has on family processes.

1. Disability crude rate per 1.000 inhabs

$$A_1 = \frac{D}{P} \times 1.000$$

where:

- D is the number of disabled persons,
- P is the total population

Further specific indicators:

Standardized rate: $A_{1,1} = \sum_x \frac{d_x}{p_x} \times w_x \times 1.000$, where

- x is the age class index (x=0-14, 15-24, 25-34, ..., 65-74, 75 and over)
- d_x is the number of disabled in the age class x
- p_x is the population in the age class x
- w_x is the standard weight for the age class x, given by S_x/S (the proportion of the standard population in the age class x). European standard weights are suggested.

Stratification levels recommended: 1) Gender; 2) Age class (0-14, 15-24, 25-34, ..., 65-74, 75 and over), 3) Type of disability, 4) Region of residence. Depending on the sample size, evaluations have to be done regarding the maximum number of stratification variables that can be used all at once (two is suggested).

Rationale: The aim is to quantify the disability phenomenon within the general population.

Source: The National Health Interview Survey with the limits explained in the Annex VII.a. Other sources could be available in order to quantify disabled persons not considered in the HIS (for instance disabled in institutions)

Computability and comparability: The indicator is computable among all EU countries. Comparability depends on the questionnaire and the definition of disability used in the HIS

Updating frequency: Long term (every 5 years)

2. Percentage of disabled persons married

$$A_2 = \frac{D_M}{D} \times 100$$

where:

- D_M is the number of disabled persons married
- D is the total number of disabled persons

Further specific indicators:

1. $A_{2,1} = \frac{ND_M}{ND} \times 100$, the same of A_2 for non disabled
2. $A_{2,2} = \frac{A_2}{A_{2,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows comparisons.

Stratification levels recommended: 1) Gender: due to the differences in life expectancy between men and women, different levels of the indicator are expected for old ages; 2) Age class (x=20-39, 40-59, 60 and over): as shown in the Rationale, age is an essential stratification variable, because it implies a different meaning of the indicator

Rationale: A_2 gives different information depending on the age class: when x=20-39 it provides information about the differences between disabled and non disabled persons in the opportunity to build up their own family, when x=60 and over it measures how much disabled persons can trust to the spouse care.

Source: The National Health Interview Survey with the limits explained in the Annex VII.a.

Computability and comparability: The indicator is computable among all EU countries. Comparability depends on the questionnaire and the definition of disability used in the HIS

Updating frequency: Long term (every 5 years)

3. Percentage of disabled persons living alone

$$A_3 = \frac{D_A}{D} \times 100$$

where:

- D_A is the number of disabled persons living alone
- D is the total number of disabled persons

Further specific indicators:

1. $A_{3,1} = \frac{ND_A}{ND} \times 100$, the same of A_3 for non disabled
2. $A_{3,2} = \frac{A_3}{A_{3,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows comparisons.

Stratification levels recommended: 1) Gender: due to the differences in life expectancy between men and women, different levels of the indicator are expected for old ages; 2) Age class (x=20-39, 40-59, 60-79, 80 and over).

Rationale: A_3 gives a measure of disabled persons, without close relatives, who need care. Moreover it is an indicator of social and emotional exclusion

Source: The National Health Interview Survey with the limits explained in the Annex VII.a.

Computability and comparability: The indicator is computable among all EU countries. Comparability depends on the questionnaire and the definition of disability used in the HIS

Updating frequency: Long term (every 5 years)

4. Percentage of households with almost 1 disabled person living therein

$$A_4 = \frac{H_D}{H} \times 100$$

where:

- H_D is the number of households with almost a disabled person living therein
- H is the total number of households

Further specific indicators: None.

Stratification levels recommended: Type of household (alone person, couple with children as child, couple with children as parent, household with only one parent as parent, household with only one parent as child, couple without children, household with more than one family, person attached to a family, other household without family)

Rationale: It is useful for monitoring the extent of households that need some help due to the presence of a disabled person.

Source: Health Interview Survey with the limits described in the Annex VII.a.

Computability and comparability: The indicator is computable among all EU countries. Comparability depends on the questionnaire and the definition of disability used in the HIS

Updating frequency: Long term (every 5 years)

5. Standardised percentage of disabled persons with a high level of education (secondary school and more)

$$A_5 = \sum_x \frac{d_{hx}}{d_x} \times w_{hx} \times 100$$

where:

- x is the age class index ($x=18-24, 25-34, \dots, 65-74, 75$ and over)
- d_{hx} is the number of disabled with a high level of education in the age class x
- d_x is the number of disabled persons in the age class x
- w_{hx} is the standard weight for the age class x , given by S_{hx}/S_h (the proportion of the standard population with a high level of education in the age class x). Standard population is given by the population of the State; weights are computable from the NHIS.

Further specific indicators:

1. $A_{5,1} = \sum_x \frac{nd_{hx}}{nd_x} \times w_{hx} \times 100$, the same of A_5 for non disabled

2. $A_{5,2} = \frac{A_5}{A_{5,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows

interesting comparisons about the different opportunities to access to high educational levels.

Stratification levels recommended: Gender

Rationale: This indicator allows to monitor the access of disabled persons to high level of education. Standardisation is necessary because the different age structure of disabled and non disabled population.

Source: Health Interview Survey with the limits described in the Annex VII.a.

Computability and comparability: The indicator is computable among all EU countries. Comparability depends on the questionnaire and the definition of disability used in the HIS

Updating frequency: Long term (every 5 years).

6. Total employment rate

$$A_6 = \frac{{}_{15-64}D_E}{{}_{15-64}D} \times 100$$

where:

- ${}_{15-64}D_E$ is the number of disabled persons employed aged 15-64;
- ${}_{15-64}D$ is the number of disabled persons aged 15-64

Further specific indicators:

1. $A_{6,1} = \frac{{}_{15-64}ND_E}{{}_{15-64}ND} \times 100$, the same of A_6 for non disabled
2. $A_{6,2} = \frac{A_6}{A_{6,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows interesting comparisons about the levels of working integration.

Stratification levels recommended: 1) Gender; 2) Age groups (15-44, 45-64), 3) Sector of activities (ILO Classification)

Rationale: Standard index for monitoring the performance target of the European Countries.

Sources: Labour Force Survey and 2002 ad hoc Module, or NHIS, or EHCP.

Computability and comparability: See the limits shown in the Annex VII.a with regard to each data source.

Updating frequency: Long term (every 5 year).

7. Rate of disabled persons under poverty line

$$A_7 = \frac{D_{PL}}{D} \times 100$$

where:

D_{PL} is the number of disabled persons with a familiar income under the poverty line

D is the total of disabled persons.

Further specific indicators:

1. $A_{7,1} = \frac{ND_{PL}}{ND} \times 100$, the same of A_7 for non disabled
2. $A_{7,2} = \frac{A_7}{A_{7,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows comparisons

Stratification levels recommended: 1) Gender; 2) Age groups (0-20, 20-39, 40-59, 60 and over); 3) type of household (alone person, couple with children as child, couple with children as parent, household with only one parent as parent, household with only one parent as child, couple without children, household with more than one family, person attached to a family, other household without family)

Rationale: It gives the degree of difficulty in economic situation of disabled persons.

Source: ECHP (European Community Household Panel) with the limits indicated in the Annex VII.a.

Computability and comparability: It is computable but the minimum level of income to identify the poverty line can change within different analysis. Sometime a family is defined poor when it has

the level of average income less than 50% of national average income; in other studies this level rises to 60% of national average income⁸.

Updating frequency: Medium term (every 3 years).

V.b Preconditions to social integration: Accessibility

Considering Accessibility as a key issue at bottom of a social integration and cohesion, means that without a full access to the material structures and to the activities of daily living disabled persons, and all persons too, can't be considered integrated and fulfilled.

There are still a number of obstacles to the integration of people with disabilities into society in different field of human life, in particular "many transport systems and public buildings continued to be inaccessible or accessible only with difficulty to people with disabilities"⁹. Moreover, the regarding of housing suitably adapted or adaptable accommodation is hard to get and prohibitively expensive.

The main objectives to promote social integration of disabled people can be focused in¹⁰:

- Introducing programmes of action to make the physical environment accessible.
- Undertaking measures to provide access to information and communication.

All MS are called upon to ascertain whether their policies took account of the need to eliminate all obstacles to full participation in social life by disabled people¹¹.

Member States were equally encouraged to promote the participation of disabled people in the implementing and following up of the policies and relevant actions.

The monitoring of accessibility with regard to the different target areas of social life needs to calculate specific indicators for each target area considered. The choice made in this paper is to calculate in the area of Accessibility some main indicators on Mobility, Transport and Access to Information and Communication and to address to the others areas to analyse the accessibility to specific social activities.

The computability of the accessibility indicators is often impossible, due to the limited availability of data source.

1. Percentage of accessible public places

$$B_1 = \frac{PP_A}{PP} \times 100$$

where:

- PP_A is the number of public places accessible
- PP is the total of public places

Further specific indicators: none.

Stratification levels recommended: The indicator has to be calculated separately for specific types of public places, such as schools, cinemas, churches, and so on.

Rationale: The objective is to monitor the effects of measures, politics and good practices oriented to eliminate architectural and barriers and to improve any kind of human activity.

⁸ EUROSTAT, *Portrait social de l'Europe*

⁹ European Commission, Equality of opportunity for people with disabilities: a new European Community Strategy, Commission Communication of 30 July 1996.

¹⁰ Rule 5 UN "Standard Rules on equalisation of Opportunities for disabled people", United Nations Resolution 1993

¹¹ Council Resolution and the representatives of the Governments of the Member States meeting within the Council on 20 December 1996 on equality opportunity for people with disabilities.

Source: data sources change depending on the different kind of places. Three cases can be identified: 1) data sources are not available at all, 2) administrative statistics are available (i.e. for schools or sports facilities), 3) a proxy indicator is available (i.e. accessible workplaces could be estimated by the 2002 ad hoc module on disability in the Labour Force Survey).

Computability and comparability: At the current time, a high level of difficulty is expected with regard to the computability and the comparability.

Updating frequency: Medium term (every 3 years).

2. Percentage of expenditure for adapting public places on GDP

$$B_2 = \frac{E_{PP}}{GDP} \times 100$$

where:

- E_{PP} is the amount of expenditure of national accounts committed to adapt public places
- GDP is the Gross Domestic Product

Further specific indicators: None.

Stratification levels recommended: The indicator has to be calculated separately for specific types of public places, such as schools, cinemas, churches, and so on.

Rationale: The aim is to monitor and to value the efforts, in monetary terms, of Members States to ensuring social participation and social inclusion of disabled persons.

Sources: National Accounts or other administrative sources, if available.

Computability and comparability: At the current time, a high level of difficulty is expected with regard to the computability and the comparability.

Updating frequency: Short term (every year).

3. Percentage of accessible public transports

$$B_3 = \frac{PT_A}{PT} \times 100$$

where:

- PT_A is the number of accessible public transports
- PT is the total number of available public transports

Further specific indicators: None

Stratification levels recommended: 1) Type of public transport (bus, train, ...) is indispensable

Rationale: Such indicator permits a monitoring of the opportunities that disabled persons are given to move in autonomy for the needs of their daily life.

Sources: At the current time no data sources are available. Anyway, at national level, when the company that manages the transport service is a public company, it should be verified if data are collected.

Computability and Comparability: computability of this indicator is very difficult. An alternative choice is to consider the following indicator “use rates of public transportation by persons with mobility impairments”. This indicator do not measure the efforts of the public administrations aimed to give adequate support to disabled persons, but the use of public transports by disabled

people can be considered also a proxy of the availability. Data source is in this case a population survey¹².

Updating frequency: Medium term (every 3 years).

4. Percentage of disabled persons having driving licence

$$B_4 = \frac{DL_D}{D} \times 100$$

where:

- DL_D is the number of special driving licences for disabled persons
- D is the total number of disabled persons.

Further specific indicators: None

Stratification levels recommended: 1) Gender and age groups (20-39, 40-59, 60 and over), 2) type of disability

Rationale: This indicator allows to analyse the diffusion of the access to private transport among disabled persons.

Sources: At international level there are no data sources, but at national level data on special driving licences for disabled persons are available, in most cases from the Ministries of Transport. Type of disability is rarely available.

Computability and Comparability: Currently, in most case it is not computable. Anyway it has to be investigated the effective availability of data in each member state.

Updating frequency: Medium term (every 3 years).

5. Percentage of persons with communication assistive needs receiving suitable assistance

$$B_5 = \frac{{}_{CAN}P_{SA}}{{}_{CAN}P} \times 100,$$

where:

- ${}_{CAN}P_{SA}$ is the number of persons with communication assistive needs receiving suitable assistance
- ${}_{CAN}P$ is the number of persons with communication assistive needs

Further specific indicators: None.

Stratification levels recommended: 1) gender and age class (20-39, 40-59, 60 and over)

Rationale: 1) Monitoring the availability of communication devices and techniques aimed to support disabled in communication; 2) Evaluate the percentage of disabled in communication with a better level of social integration

Source: with regard to the working place, the 2002 LFS with the ad-hoc module on disability, for those working. Anyway, some national population surveys collect this information.

Computability and comparability: items related to the use of devices are rarely included in the National Health Interview Surveys. So, the indicator will be available only on the occasion of the LFS in 2002. Anyway, the inclusion of such items also in the NHIS is desirable.

Updating frequency: Long term (every 5 years)

¹² In Italy the indicator is computable from the annual survey “Everyday life aspects”.

6. Percentage of persons with mobility assistive needs receiving suitable assistance

$$B_6 = \frac{{}_{MAN}P_{SA}}{{}_{MAN}P} \times 100,$$

where:

- ${}_{MAN}P_{SA}$ is the number of persons with mobility assistive needs receiving suitable assistance
- ${}_{MAN}P$ is the number of persons with mobility assistive needs

Further specific indicators: None.

Stratification levels recommended: 1) gender and age class (20-39, 40-59, 60 and over)

Rationale: 1) Monitoring the availability of mobility devices and techniques aimed to support disabled in mobility; 2) Evaluate the percentage of disabled in mobility with a better level of social integration

Source: with regard to the working place, the 2002 LFS with the ad-hoc module on disability. Anyway, some national population surveys collect this information.

Computability and comparability: items related to the use of devices are rarely included in the National Health Interview Surveys. So, the indicator will be available only on the occasion of the LFS in 2002. Anyway, the inclusion of such items also in the NHIS is desirable.

Updating frequency: Long term (every 5 years)

7. Percentage of adapted web sites

$$B_7 = \frac{WS_A}{WS} \times 100$$

where:

- WS_A is the number of adapted web sites
- WS is the total number of web sites

Further specific indicators: none

Stratification levels recommended: None.

Rationale: Access to communication technologies enhances the diffusion of culture, and increases the opportunities to be informed about free time and leisure activities.

Sources: see *Computability and Comparability*:

Computability and Comparability: the indicator is particularly important in case of web sites belonging to a public administration. Computation could be limited to this case, so the computability of the total number of web sites is simplified (in fact, in this case the list of web sites is available by national authorities). Calculation of accessible web sites depends if a national standard is available, another choice is to consider the same standard for all MS (i.e. “Bobby approved” from CAST). Anyway, data collection is arduous, but possible.

Updating frequency: Short term (every year).

V.c Preconditions to social integration: Health and health service

Prevention, health care and rehabilitation are key elements for integration policies directed to disabled persons, since without effective assistance and proper rehabilitation measures, their

position of social disadvantage may be worsened. Primary prevention can also be considered as a pivotal element in observance of the EU policies which aims at supporting the appropriate bases for the integration rather than at providing support or means in an hindsight perspective.¹³

Disabled persons are those who need major health resources and for whom countries allocate an ever-increasing number of resources.

It is essential to precisely quantify the extent of the problem related to the demand of health services by the disabled persons in order to understand how an integration policy for the disabled must focus on their needs related to health, treatment and rehabilitation services. Also prevention is to be considered a key issue, since thanks to the progress achieved in medical research, prevention offers an ever-increasing number of intervention tools for public health policies.

The UN Standard Rules and the Resolution of the EU Council of Ministers¹⁴ are the most significant international tools to guarantee the observance of human and civil rights for disabled people.

The principles to be implemented in the health field, which come from these documents, can be expressed with the following concepts:

1. Prevention. It is an action aimed at preventing the occurrence of physical, intellectual, psychical or sensorial damages (primary prevention), and preventing damages that cause a permanent physical limitation or disabilities (secondary prevention);
2. Rehabilitation. To rehabilitate is a permanent process by means of which the intention is to place people with disabilities in a condition to reach and maintain their optimal functional level at physical, sensorial, intellectual, psychiatric, and/or social level by providing them the tools to change their lives through a higher degree of independence and self-determination. Hence, the aim of the rehabilitation is not to recover but to offer tools and solutions in order to achieve an autonomous and self-determined life;
3. Equal opportunities. To carry out equal opportunities means to put into effect processes by means of which different societies and different environments are made accessible to everyone. To promote the rights of disabled implies also to facilitate access to the full range of appropriate supports and health services, inside the structures in charge, possibly inside a comfortable environment, which could be the family or structures with a human nature, thus avoiding large structures.

From the basis concepts we extrapolated the “dimensions” to be investigated through the selected indicators, namely: needs of health services, offer of health services, cost of health services in relation to disability, and implementation of preventive policies.

Comparability of health care data is critical to better interpretation and understanding of such data.¹⁵ The different organisation of the health care systems affects the comparability of health indicators among EU countries.

1. Disability-free life expectancy at birth (Sullivan method)

$$C_1 = DFLE_0 = \frac{wdT_0}{l_0}$$

where, for age x:

¹³ Public health community action programmes 1996-2000 and 2001-2006

¹⁴ Resolution of the European Council on “Equality of opportunity for people with disabilities”, 20th December 1996.

¹⁵ EUCOMP – Towards Comparable Health Care Data in the European Union, Parts 1-3, 2000

- ${}_{wd}T_x = \sum_{i=x+5}^{85} (1 - \pi_i) \cdot L_i$, are the total years lived without disability from age x, L_i =person years lived in age interval (i,i+4) and π_i is the proportion of those in the age group with disability beginning age x

- l_x is the probability of survival to age x

Further specific indicators: DFLE₁₅, DFLE₄₅, DFLE₆₅, DFLE₇₅.

Stratification levels recommended: Gender

Rationale: monitoring population health and making comparisons between countries, within countries over time.

Sources: abridged life table and Health Interview Survey.

Computability and Comparability: Because the HIS don't give the disability prevalence at birth, an estimate of π_0 is necessary. π_x should also be adjusted to incorporate the institutionalized population. Comparability depends on the questionnaire and the definition of disability used in the HIS

Updating frequency: Long term (every 5 years).

2. Standardised percentage of disabled persons with two or more chronic diseases

$$C_2 = \sum_x \frac{d_{dx}}{d_x} \times w_{dx} \times 100$$

where:

- x is the age class index (x=0-14, 15-24, 25-34, ..., 65-74, 75 and over)
- d_{dx} is the number of disabled with two or more chronic diseases in the age class x
- d_x is the number of disabled persons in the age class x
- w_{dx} is the standard weight for the age class x, given by S_{dx}/S_d (the proportion of the standard population with two or more chronic diseases in the age class x). Standard population is given by the population of the Country; weights are computable from the NHIS.

Further specific indicators:

3. $C_{2,1} = \sum_x \frac{nd_{dx}}{nd_x} \times w_{dx} \times 100$, the same of C_2 for non disabled

4. $C_{2,2} = \frac{C_2}{C_{2,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows comparisons.

Stratification levels recommended: Gender

Source: Health Interview Survey with the limits described in the Annex VII.a.

Computability and comparability: The indicator is computable among all EU countries. Comparability depends on the questionnaire and the definition of disability used in the HIS

Updating frequency: Long term (every 5 years).

3. Rate of hospitalisation

$$C_3 = \frac{D_H}{D} \times 100$$

where:

- D_H is the number of disabled hospitalised in the preceding year

- D is the total number of disabled

Further specific indicators:

1. $C_{3,1} = \frac{ND_H}{ND} \times 100$, the same of C_3 for non disabled
2. $C_{3,2} = \frac{C_3}{C_{3,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows comparisons.

Stratification levels recommended: 1) Gender and age (0-19, 20-39, 40-59, 60-69, 70 and over)

Rationale: approximate indicator of the health care needs expressed by the disabled.

Source: Health Interview Survey with the limits described in the Annex VII.a.

Computability and comparability: The indicator is computable among all EU countries. Comparability depends on the questionnaire and the definition of disability used in the HIS.

Updating frequency: long term (every 5 years).

4. Proportion of health expenditure for disabled persons as part of the total health expenditure

$$C_4 = \frac{HE_D}{HE}$$

where:

- HE_D is the health expenditure for disabled persons
- HE is the total health expenditure.

Further specific indicators: None

Stratification levels recommended: 1) Expense item (health services, in-home services, prostheses, drugs), 2) Region

Rationale: It indicates the "cost of disability" for the health services.

Source: At present no source is available. In the near future, the new system of health account proposed by OECD¹⁶, organised by function, should provide relevant data.

Computability and comparability: At present the indicator is not computable. An estimate is possible exploiting the NHIS data, for the proportion of use of health services by disabled persons, and the HFA-WHO database, for the data on the total health expenditure. It is important to analyse the health expenditure considering how the single national health system is organised in terms of extent of coverage by the public health system. The health care expenditure for disability may come not only from the health system but also from the welfare system, that has to be taken into account in order to have a complete view of the situation.

Updating frequency: Medium term (every 3 years).

5. Percentage of the total expense for prevention and public health on the total of the health expenditure.

$$C_5 = \frac{HE_P}{HE}$$

where:

- HE_P is the health expenditure for prevention and public health

¹⁶ New System of Health Account. OECD 2000

- HE is the total health expenditure.

Further specific indicators: None.

Stratification levels recommended: 1) Expense item (health services, in-home services, prostheses, drugs). 2) Region

Rationale: Prevention is the main objective of the health programmes of EU countries. The amount of health budget dedicated to prevention indicates the effort of the countries in this field.

Source: OECD Health data.

Computability and comparability: At present the indicator is computable in only a few of the EU countries.

Updating frequency: Long term (every 5 years)

V.d Preconditions to social integration: Social Protection

The goal of modern welfare systems is just to ensure, according to the historical development of every country, the preservation of fundamental rights of all people: granting a minimum income, remunerated job, housing, health care, education, equal opportunities of social integration in all fields of human life.

A high standard of Social Protection Systems is fundamental in the field of disability, but all MS agree on that the only income solution is not necessarily sufficient to realise a full participation in the society by the less protected categories.

Following European guidelines it emerges that MS have full autonomy in the responsibility about social protection systems¹⁷, but at the same time it has been highlighted the organising and co-ordinating role of European Union¹⁸.

1. Percentage of social expenditure in “Disability function”¹⁹ on GDP

$$D_1 = \frac{SE_D}{GDP} \times 100$$

where:

- SE_D is the social expenditure for disabled persons
- GDP is the Gross Domestic Product

Further specific indicators: None.

Stratification levels recommended: None.

Rationale: It is a key indicator aimed to measure the economic care to financing social benefits for disabled persons.

Source: ESSPROS European System of integrated Social Protection Statistics.

Computability and comparability: It is computable. This indicator doesn't include tax allowances and other compulsory levies for social amount. In the ESSPROS “Disability function” includes benefits aimed to:

- provide an income to persons below standard retirement age whose ability to work and earn is impaired beyond a minimum level laid down by legislation by a physical or mental disability;
- provide rehabilitation services specifically required by disabilities;
- provide goods and services other than medical care to disabled persons.

¹⁷ Recommendation of the Council on the convergence of social protection objectives and policies, 1992

¹⁸ European Community, "The future of Social Protection", COM (95) 466 final.

¹⁹ Eurostat, ESSPROS MANUAL 1996

Updating frequency: Short term (every year).

2. Percentage of social expenditure for disability pension on the total of pension expenditure

$$D_2 = \frac{PE_D}{PE} \times 100$$

where:

- PE_D is the amount of expenditure for disability pension
- PE is the total expenditure for pension systems.

Further specific indicators: None.

Stratification levels recommended: None.

Rationale: The indicator allows to evaluate the financial impact of disability pension on the total of expenditure for funding pension at National Accountability level.

Source: ESSPROS European System of integrated Social Protection Statistics.

Computability and Comparability: It is computable.

Updating frequency: Short term (every year).

3. Ratio between benefit in kind (services) and cash benefit (monetary benefits)

$$D_3 = \frac{KB}{CB}$$

where:

- KB is benefit in kind
- CB is cash benefit

Further specific indicators: None

Stratification levels recommended: None

Rationale: In this case the aim is to value and to monitor the guidelines of the European countries about Social Policy on disability.

Source: ESSPROS European System of integrated Social Protection Statistics.

Computability and comparability : It is computable. The ESSPROS method defines: benefit in kind as accommodation, assistance in carrying out daily tasks, rehabilitation, and other benefits; cash benefit as disability pension, early retirement benefits due to reduced capacity to work, care allowance, economic integration of the disabled persons and other benefits.

Updating frequency: Long term (every 5 years).

V.e Target Areas: Education and school integration

Education has been identified as one of the three most important target areas to analyse within this project, since it represents a fundamental factor of integration of disabled persons life. In fact, many of the reasons on which social exclusion of disabled persons is based, come from a low and insufficient level of education and training. Moreover, still nowadays many disabled students are segregated in special public education systems.

Anyway, the right of students with disabilities to be educated in regular and mainstreamed schools is becoming more and more accepted in most countries, and many national reforms such as International (UN Standard Rules²⁰) and European guidelines are being put in place positive actions

²⁰ UN Standard Rules N.6 on "Education"

to achieve this goal. Education systems have to be reconsidered to meet the needs of all students, looking forward toward a more complex project of life taking into account the effective outcomes of this process in terms of employment opportunity, economic and personal independence.

The gathering of statistics regarding *students with disabilities*, suitable for policy relevant comparisons among the different EU countries with different education systems and adopting different definitions of disability, requires much effort. The recent OECD study on “Special Needs Education”²¹ has faced this problem, starting from the identification of a harmonized definition of “students with special educational needs”. At the beginning, students with disabilities, learning difficulties and disadvantages were included within this generic definition. So, it was agreed to further sub-divide this group of students into three cross-national categories. The Countries involved in the Project were invited to re-classify their data into this new framework. The operational definition of the three cross-national categories are the following:

Category A = students whose disabilities have clear biological causes (such as blind and partially sighted, deaf and partially hearing, severe and profound mental handicap, multiple handicaps..);

Category B = students who are experiencing learning and behaviour difficulties for no particular reason;

Category C = students who have difficulties arising from disadvantages (primarily from socio-economic, cultural and/or linguistic factors).

The levels A, B, and C do not really stratify the population of disabled persons. They cover the population of those with special educational needs defined as above mentioned. Disabled persons are mainly covered in Category A, although for some countries some of them may be included in B. From the point of view of school integration Category A is the most relevant, since those in B and C are in the main already integrated.

The comparisons allowed are limited to primary and lower secondary education, in the interests of data quality and availability.

1. Standardised literacy rate of disabled aged 15 and over

$$E_1 = \sum_x \frac{d_{lx}}{d_x} \times w_{lx} \times 100$$

where:

- d_{lx} is the number of disabled in age class x ($x=18-24, 25-34, \dots, 65-74, 75$ and over) who can read and write
- d_x is the number of disabled in age class x
- w_{lx} is the standard weight for the age class x , given by S_{lx}/S_1 (the proportion of the standard population that can read and write in the age class x). Standard population is given by the population of the Country; weights are computable from the NHIS.

Further specific indicators:

1. $E_{1,1} = \sum_x \frac{nd_{lx}}{nd_x} \times w_{lx} \times 100$, the same of E_1 for non disabled

2. $E_{1,2} = \frac{E_1}{E_{1,1}} \times 100$, the ratio allows to monitor the different opportunities in accessing up to minimum levels of education in both disabled and non disabled populations.

Stratification levels recommended: Gender

²¹ OECD, *Special Needs Education*, statistics and indicators, 2000.

Rationale: This indicator offers a dimension of the risk of disabled persons to be excluded from any integration process.

Source: Health Interview Survey with the limits described in the Annex VII.a.

Computability and comparability: The indicator is computable among all EU countries. Comparability depends on the questionnaire and the definition of disability used in the HIS

Updating frequency: Long term (every 5 years).

2. Proportion of students in cross-national category A as a percentage of all students in primary and lower secondary education

$$E_2 = \frac{S_A}{S} \times 100$$

where:

- S_A is the total number of students in cross-national category A
- S is the number of all students in primary and lower secondary education.

Specific indicators: same indicator for cross-national categories B and C of students with special needs.

Stratification levels recommended: Gender and age (annual basis)

Rationale: This indicator quantify the number of students, for whom additional resources are allocated.

Sources: The OECD data collection instrument to be linked to UOE (UNESCO/OECD/EUROSTAT) data collection.

Computability and comparability: Currently, this indicator is computable, but the level of comparability is influenced by the different educationally based definition of disability in each Country. Stratification by gender is possible in Belgium, Finland, Luxembourg, the Netherlands, Spain, Sweden, United Kingdom

Updating frequency: Short term (every year).

3. Number of special schools relative to total school population

$$E_3 = \frac{SS}{P_s} \times 100,000$$

where:

- SS is the number of special schools
- P_s is the total primary and lower secondary school population.

Specific indicators: Average size of special schools

Stratification levels recommended: 1) Type of school (private or public).

Rationale: This indicator is useful in order to monitor the endurance of a separation and segregation culture.

Sources: The OECD pilot data collection instrument to be linked to UOE (UNESCO/OECD/EUROSTAT) data collection.

Computability and comparability: the indicator is computable; for the comparability it is worthwhile remember that: 1) Belgium includes upper secondary students (ISCED3), 2) Finland still considers the school year 1996; 3) Greek and Portuguese data refer to all national categories within national definition; 4) Portuguese data refer only to schools coming under Ministry of Education.

Updating frequency: Short term (every year)

4. Proportion of students in cross-national category A integrated in regular classes

$$E_4 = \frac{{}_A S_R}{{}_A S}$$

where:

- ${}_A S_R$ is the number of students in cross-national category A integrated in regular classes
- ${}_A S$ is the total number of students in cross-national category A, given by the students in regular classes and in special classes.

Specific indicators:

1. $E_{4,1} = \frac{{}_B S_R}{{}_B S}$, same indicator for cross-national category B of students with special needs.
2. $E_{4,2} = \frac{{}_C S_R}{{}_C S}$, same indicator for cross-national category C of students with special needs.

Stratification levels recommended: 1) Gender and age (annual)

Rationale: This indicator is useful in order to monitor both the extent of integration of disabled students within regular classes in mainstreamed schools.

Source: The OECD data collection instrument to be linked to UOE (UNESCO/OECD/EUROSTAT) data collection.

Computability and comparability: Currently it is computable.

Updating frequency: Short term (every year).

5. Disabled students/support staff (teacher) ratio in special schools

$$E_5 = \frac{DS_{SS}}{ST_{SS}}$$

where:

- DS_{SS} is the number of disabled students in special schools
- TS_{SS} is the number of support teachers in special schools

Specific indicators:

$$E_{5,1} = \frac{DS_{RS}}{ST_{RS}}, \text{ same indicator for special classes in regular schools.}$$

Stratification levels recommended: Type of school (public and private), level of education (primary and lower secondary)

Rationale: Measuring the additional resources allocated for students with special needs.

Source: The OECD data collection instrument to be linked to UOE (UNESCO/OECD/EUROSTAT) data collection.

Computability and comparability: This indicator is rarely computable, except for special schools. Only a few countries can split these information into primary and lower secondary level of education. Only for three countries (Greece, Ireland and Netherlands) data on national categories is available.

Updating frequency: Short term (every year).

6. Attendance in colleges and universities

$$E_6 = \frac{{}_{19-35}D_{AU}}{{}_{19-35}D}$$

where:

- ${}_{19-35}D_{AU}$ is the number of disabled students aged 19-35 that attend college or university
- ${}_{19-35}D$ is the number of disabled aged 19-35

Specific indicators:

$$E_{6,1} = \frac{{}_{19-35}ND_{AU}}{{}_{19-35}ND}, \text{ same indicator for non disabled}$$

Stratification levels recommended: gender

Rationale: Measuring the participation of disabled to higher education.

Source: University statistics or population surveys

Computability and comparability: because do not exist a established data source, computability and comparability cannot be treated

Updating frequency: Short term (every year).

V.f Target Areas: Employment and Training

Employment is a basic condition to enable all individuals to reach a full economic independence and an effective social inclusion and integration.

The UN Standard Rules clearly refer to the right to work of disabled persons: *The right to work is a fundamental right of all individuals, being closely linked to human dignity...If the disabled person is able to work (even if with mechanical aids), all the opportunities to reintroduce him/her in the working world should be tried out.*

The European Commission has been facing employment related issues for a long time, and it has been launching some political guidelines to MS aimed to combat unemployment. The Amsterdam Treaty and the Luxembourg Summit represent two basic moments in the definition of common goals and guidelines directed to improve the occupational levels.

Guideline N.9 refers specifically to disabled persons and in a more general way to those disadvantaged people and their right to a full integration in the labour market. Many other guidelines are very important too: for example the guideline N.3 that refers to the problem of long-term unemployment involving overall those in a non competitive condition within the labour market (such as the disabled persons). Moreover the guideline N.6 focus on the importance of a long-life training: this is a topic really important for disabled persons who don't gain work due to a non adequate skill.

The main reference used for the description of this thematic area is the *Joint Employment Report*, produced every year by the European Commission and adopted by the Council of the European Union, on the basis of what is stated in occasion of the Luxembourg Summit. The indicators proposed are a small and selected group of those included in the two previous progress reports, including the changes needed for disabled persons.

1. Unemployment rate

$$F_1 = \frac{{}_{15-64}D_U}{{}_{15-64}D_{LF}} \times 100$$

where:

- ${}_{15-64}D_U$ is the number of disabled persons unemployed aged 15-64;
- D_{LF} is the number of disabled persons belonging to labour force aged 15-64

Further specific indicators:

1. $F_{1,1} = \frac{{}_{15-64}ND_U}{{}_{15-64}ND_{LF}} \times 100$, the same of F_1 for non disabled
2. $F_{1,2} = \frac{F_1}{F_{1,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows interesting comparisons about the levels of working exclusion.

3. Long-term unemployment rate, regarding an unemployment length equal to 2 years or higher:

$$F_{1,3} = \frac{{}_{15-64}D_U^{2+}}{{}_{15-64}D_{LF}} \times 100$$

Stratification levels recommended: Gender and age groups (15-24 in particular, in order to monitor youth unemployment), type of disability

Rationale: Standard index for assessing the strategy against unemployment.

Source: Labour Force Survey and 2002 ad hoc module on disability in LFS in 2001, or ECHP (but it is not possible to stratify by type of disability), or NHIS (but it is not possible to calculate the long-term unemployment rate).

Computability and comparability: The indicator is computable from the LFS only on the occasion of the ad-hoc module on disability. In order to have a time series of the indicator, ECHP can be considered as data source.

Updating frequency: Short term (every year)

2. MEDIUM LENGTH OF UNEMPLOYMENT

$$F_2 = \frac{\sum_{i=1}^{D_U} {}_D L_i}{{}_D U}$$

where:

- $i=1 \dots N$ is the index of unit
- ${}_D U$ is the total number of disabled persons unemployed
- ${}_D L_i$ is the length of unemployment of disabled person i .

Further specific indicators:

1. $F_{2,1} = \frac{\sum_{i=1}^{ND_U} {}_{ND} L_i}{{}_{ND} U}$, the same of F_2 for non disabled
2. $F_{2,2} = \frac{F_2}{F_{2,1}} \times 100$, the ratio between the indicators calculated for disabled and non disabled allows interesting comparisons about the seriousness of unemployment.

Stratification levels recommended: Gender and age groups (to 15 to 64 years using ten-years or twenty-years classes), type of disability.

Rationale: To identify the most serious situation of working and social exclusion.

Source: Labour Force Survey and 2002 ad hoc module on disability, or ECHP (but it is not possible stratify by type of disability).

Computability and comparability: The indicator is computable from the LFS only on the occasion of the ad-hoc module on disability. In order to have a time series of the indicator, the ECHP can be considered as data source.

Updating frequency: Short term (every year)

3. Disability pay gap

$$F_3 = \frac{HE_D}{HE_{ND}}$$

where:

- HE_D is the disabled's medium hourly earnings for paid employees at work 15+ hours
- HE_{ND} is the non disabled's medium hourly earnings for paid employees at work 15+ hours

Specific indicators: None

Stratification levels recommended: 1) Gender, 2) type of disability, 3) kind of economic activity

Rationale: Indicator to assessing equality between disabled and non disabled employees.

Source: ECHP (European Community Household Panel).

Computability and comparability: This indicator is computable from the ECHP, but the type of disability is not available. Anyway, it is included because it represents an important stratification variable.

Updating frequency: Long term (every 5 years)

4. Ratio of active labour market expenditure for the disabled

$$F_4 = \frac{\%GDP_D}{F_1}$$

where:

- $\%GDP_D$ is the % share of expenditure on labour market policies for disabled in GDP

The % of GDP is divided by total unemployment rate, because the share of expenditure in GDP gives a distorted view of the real importance of active policies in the different member States, since the number of unemployed people to which such policies are addressed varies substantially²².

Specific indicators: None.

Stratification levels recommended: none.

Rationale: It is an indicator of the policy effort undertaken by national authorities in upgrading the skills of the unemployed and providing them with job opportunities.

Source: OECD Employment Outlook for the expenditure, HIS or LFS with ad hoc module on disability for the unemployment rate.

Computability and comparability: Expenditure for disabled is one of the levels considered in the OECD Employment Outlook. Eurostat is developing a new data base allowing for detailed information on expenditure, as well as beneficiaries²³.

Updating frequency: Medium term (every 3 years)

²² Joint Employment Report 1999, Part I: the European Union, 13607/99 SOC 438 ECOFIN 268

²³ ibidem

5. Participation Index

$$F_5 = \frac{{}_{15-64}D_{ET}}{{}_{15-64}D} \times 100$$

where:

- ${}_{15-64}D_{ET}$ is the number of disabled persons aged 15-64 participating in education and training
- ${}_{15-64}D$ is the total number of disabled aged 15-64

Specific indicators: None

Stratification levels recommended: 1) Gender and age (15-44, 45-64); 2) type of disability.

Rationale: It is an indicator of the policy effort undertaken by national authorities in upgrading the skills of the unemployed and providing them with job opportunities.

Source: Labour Force Survey and the 2002 ad-hoc module on disability in LFS.

Computability and comparability: This indicator is computable from the LFS only on the occasion of the ad-hoc module on disability. Other data sources can be considered (ECHP).

Updating frequency: Medium term (every 3 years).

V.g Target Areas: Social Participation

The social participation of disabled persons is an important indicator of the effectiveness of integration policies, since it shows the extent of inclusion of persons with different kinds of disabilities and difficulties in the cultural, recreational, political and associative activities of the daily life.

The UN Standard Rules²⁴ foster all those measures aimed to ensure that persons with disabilities have equal opportunities for participating in cultural activities, in recreation and sports on an equal basis.

Other documents and normative guidelines²⁵ stress the importance of enabling disabled persons to communicate with relatives, friends and colleagues, to travel, to participate in sports, cultural and leisure time activities. In order to encourage disabled persons to participate in social life as much as possible, all of them should have the main communication means: radio, television, newspapers and telephone. Of course, measures should be studied in order to overcome the barriers that prevent an adequate use of these communication means by the disabled persons: using sign language on television, adapting telephone equipment for people with hearing problems, distributing newspaper in Braille, activating telecommunication services such as "minitel", and providing for the use of sign language in public places. Of course, this should all be accomplished at costs adequate to family budgets.

1. Standardised percentage of participation in social, cultural and political activities

$$G_1 = \sum_x \frac{{}_{SA}d_x}{d_x} \times {}_{SA}w_x \times 100$$

where:

²⁴ UN Standard Rules N.10 "Culture", N.11 "Recreation and sports", N.12 "Religion".

²⁵ European Council, Recommendation N.R(92)6 on "A Coherent Policy for People with Disabilities", Chapter VIII entitled "Social integration and environment" divided in the following sections: Accessibility, Communication, Sport, Leisure time and cultural activities.

- ${}_{SA}d_x$ is the number of disabled persons aged (x, x+9) - x=15, 25, 35, 45, 55, ... - who declare to take part in social, cultural and political activities
- d_x is the number of disabled persons aged (x, x+9) - x=15, 25, 35, 45, 55,
- ${}_{SA}w_x$ is the proportion of the standard population (disabled and non disabled who take part in social, cultural and political activities) aged (x, x+9).

Specific indicators:

1. $G_{1,1} = \sum_x \frac{{}_{SA}nd_x}{nd_x} \times {}_{SA}w_x \times 100$, the same of G_1 for non disabled
2. $G_{1,2} = \frac{G_1}{G_{1,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows interesting comparisons.

Stratification levels recommended: 1) Gender. It should be worthwhile to consider the professional condition and the educational level too, on the basis of the results of the recent Report of the European Commission entitled “Social Portrait of Europe 2000”, in which a significant influence of working activity and of the education level on the participation to such activities has been revealed.

Rationale: This indicator show the extent of the community inclusion of disabled persons.

Source: ECHP with the limits described in the Annex VII.a. Standard population is calculable from ECHP too.

Computability and comparability: Currently, this indicator is computable but it is worthwhile to stress the limits of the ECHP. In fact, due to the sample size and the level of non-response in some Countries, the actual data source requires particular circumspection in using stratification variables.

Updating frequency: Long term (every 5 years).

2. Standardised percentage of participation in social relations

$$G_2 = \sum_x \frac{{}_{SR}d_x}{d_x} \times {}_{SR}w_x \times 100$$

where:

- ${}_{SR}d_x$ is the number of disabled persons aged (x, x+9) - x=15, 25, 35, 45, 55, ... - who declare to talk to their neighbours, to meet people at home or elsewhere and have spoken to someone outside the household during the last week
- d_x is the number of disabled persons aged (x, x+9) - x=15, 25, 35, 45, 55,
- ${}_{SR}w_x$ is the proportion of the standard population (disabled and non disabled who talk to their neighbours, to meet people at home or elsewhere and have spoken to someone outside the household during the last week) aged (x, x+9).

Specific indicators:

3. $G_{2,1} = \sum_x \frac{{}_{SR}nd_x}{nd_x} \times {}_{SR}w_x \times 100$, the same of G_2 for non disabled
4. $G_{2,2} = \frac{G_2}{G_{2,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows interesting comparisons.

Stratification levels recommended: 1) Gender. It should be worthwhile to consider the professional condition and the educational level too, on the basis of the results of the recent Report of the European Commission entitled “Social Portrait of Europe 2000”, in which a significant influence of working activity and of the education level on the participation to such activities has been revealed.

Rationale: This indicator is useful for two reasons:

- a) it permits to know how many disabled persons are in contact with people other than members of their family and how many are able to gain relationships with friends and colleagues, neighbours, and any other person;
- b) it offers an indirect measure of the possible isolation condition of disabled persons who are almost always alone and segregated in their home.

Source: ECHP with the limits described in the Annex VII.a. Standard population is calculable from ECHP too.

Computability and comparability: Currently, this indicator is computable but it is worthwhile to stress the limits of the ECHP. In fact, due to the sample size and the level of non-response in some Countries, the actual data source requires particular circumspection in using stratification variables.

Updating frequency: Long term (every 5 years).

3. Standardised percentage of participation in sportive activities

$$G_3 = \sum_x \frac{SP d_x}{d_x} \times_{SP} w_x \times 100$$

where:

- SPd_x is the number of disabled persons aged (x, x+9) - x=15, 25, 35, 45, 55, ... - who declare to do some physical exercise
- d_x is the number of disabled persons aged (x, x+9) - x=15, 25, 35, 45, 55,
- SPW_x is the proportion of the standard population (disabled and non disabled who declare to do some physical exercise) aged (x, x+9).

Specific indicators:

1. $G_{3,1} = \sum_x \frac{SP nd_x}{nd_x} \times_{SP} w_x \times 100$, the same of G_3 for non disabled
2. $G_{3,2} = \frac{G_3}{G_{3,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows interesting comparisons.

Stratification levels recommended: 1) Gender; 2) type of disability

Rationale: This indicator is useful for monitoring the extent of involvement of disabled persons in physical activities.

Source: Health Interview Survey with the limits described in the Annex VII.a.

Computability and comparability: The indicator is computable among all EU countries. Comparability depends on the questionnaire and the definition of disability used from the HIS, and also on the items about sport.

Updating frequency: Long term (every 5 years).

4. Standardised percentage of participation in the vote

$$G_4 = \sum_x \frac{V d_x}{d_x} \times_V w_x \times 100$$

where:

- Vd_x is the number of disabled persons aged (x, x+9) - x=15, 25, 35, 45, 55, ... - who declare to vote during the last national election (or European election)

- d_x is the number of disabled persons aged (x, x+9) - x=15, 25, 35, 45, 55,
- ${}_v w_x$ is the proportion of the standard population (disabled and non disabled who declare to vote during the last national election or European election) aged (x, x+9).

Specific indicators:

1. $G_{4,1} = \sum_x \frac{{}_v nd_x}{nd_x} \times {}_v w_x \times 100$, the same of G_4 for non disabled
2. $G_{4,2} = \frac{G_4}{G_{4,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows interesting comparisons.

Stratification levels recommended: 1) Gender; 2) type of disability

Rationale: measure of both the extent of interest that disabled persons have into socio-political issues, and of their effective possibility to reach the electoral stations.

Source: Currently, no data sources are available²⁶.

Computability and comparability: No consideration is possible to do.

Updating frequency: Long term (every 5 years).

5. Standardised percentage of disabled persons attending religious services and events.

$$G_5 = \sum_x \frac{{}_R d_x}{d_x} \times {}_R w_x \times 100$$

where:

- ${}_R d_x$ is the number of disabled persons aged (x, x+9) - x=15, 25, 35, 45, 55, ... - who declare to attend religious services and events
- d_x is the number of disabled persons aged (x, x+9) - x=15, 25, 35, 45, 55,
- ${}_R w_x$ is the proportion of the standard population (disabled and non disabled who declare to attend religious services and events) aged (x, x+9).

Specific indicators:

3. $G_{5,1} = \sum_x \frac{{}_R nd_x}{nd_x} \times {}_R w_x \times 100$, the same of G_5 for non disabled
4. $G_{5,2} = \frac{G_5}{G_{5,1}} \times 100$, the ratio between the rates calculated for disabled and non disabled allows interesting comparisons.

Stratification levels recommended: 1) Gender; 2) type of disability

Rationale: measure of both the extent of interest that disabled persons have into religious events, and of their effective possibility to reach the place of worship.

Source: Currently, no data sources are available.

Computability and comparability: the indicator could be computed from population surveys, but at the moment it is not available

Updating frequency: Long term (every 5 years).

²⁶ In Italy the survey "Everyday Life Aspects" collects data about those disabled persons who voted at the last European election and at the last Referendum (1999).

VI. OTHER RELEVANT ASPECTS OF THE PHENOMENON

VI.a Disabled Persons in Institution

The National Health Interview Survey is probably the most important source about disability, but almost always the NHIS do not consider people living in institution. To have some data about disabled persons in institution it is necessary to refer to ad hoc survey or to administrative sources. There are some example of survey that point out institution situation: Austria with the Microcensus of Physical Disabilities collects information about people in institution and France with the National Disabilities Interview points out disabled persons in institution aged 15 and over.

A possible solution to have a complete picture of these disabled persons living in institution is to use the Census of Cohabitations and introducing in the related questionnaire an item about the self-sufficiency of people living in the cohabitation.

VI.b A set of subjective indicators about individual satisfaction

1. Health

1.1 Proportion of disabled people who perceived their health status «very bad».

It is to estimate the proportion of disabled people who perceive their health as very bad. The indicator is affected by not good health departure conditions of the disabled people, but a monitoring of this indicator can be useful to understand the success of programs dedicated to disabled people. Source data are the NHISs. The indicator should be stratified by gender and age, as the age influences the disability degree and the perception of the health status. Dealing with a subjective qualitative measure, it is to be critically used. The different economic and social conditions, and the different behavior, in the countries may affect the comparability of the indicator.

1.2 Percentage of disabled persons satisfied with health services.

The percentage of people who are very or fairly satisfied with health services in their own country. Source data is the EUROBAROMETER 1998. The indicator is influenced by the different health systems and economic and social condition in the EU countries.

2. Social protection

2.1. Percentage of disabled persons satisfied with their financial situation

The aim of this indicator is to value the perception of the economic situation of disabled and non disabled persons, and to compare living conditions through stratification variables. It could be useful to compute this indicator for non disabled persons too, and to stratify by gender and age. Data source is the ECHP (European Community Household Panel).

3. Education

3.1 Percentage of disabled persons satisfied with their education and professional training

It is the percentage of disabled persons fairly or very satisfied with the education level reached and the professional training experimented. Data source is the ECHP.

4. Employment

4.1 Percentage of disabled persons satisfied with their working activity

It is the percentage of disabled persons fairly or very satisfied with their working activity. Data source is the ECHP.

5. *Social Participation*

5.1 *Percentage of disabled persons satisfied with leisure time*

It is the percentage of disabled persons fairly or very satisfied with their leisure and free-time. Data source is the ECHP.

6. *Housing*

6.1 *Percentage of disabled persons satisfied with housing conditions*

It is the percentage of disabled persons fairly or very satisfied with their housing conditions. Data source is the ECHP.

VI.c A short set of indicators related to emerging aspects of the phenomenon

1. *Disabled and Violence*

1.1 *Number of disabled persons who have been victim of a form of abuse or injury.*

Abuse and maltreatment are suffered by the weakest among the weak: women, children, those in severe conditions and mentally retarded disabled persons²⁷. It is necessary to act to prevent and to eradicate the causes of violence and abuse afflicted on disabled persons at the root. It is necessary to promote and foster good practices, raise the awareness that these phenomena exist, even if in a very repent form, and strengthen the self-esteem of the persons suffering these serious offences to human dignity.

At the present time **no data is available.**

2. *Disabled and Communication technologies*

2.1 *Number of disabled persons currently using a computer*

At the present time there is a broad consensus that technological progress in the field of information and communication technologies will deeply affect the structure of human society. Access to information is considered a central factor in the guarantee of an independent life: it means offering to everyone the same opportunities for choice. On 8th December 1999 the European Commission launched the Project “Europe – An Information Society for Everyone” which proposes high aims for the participation of everyone in the advantages of the information society. Of the 10 sectors into which the project is articulated, one is completely dedicated to the disabled and their specific needs, for the improvement of their access to the information society. For this purpose some “standardisation” bodies (CEN/CENELEC/ETSI) are working in cooperation with organisations representing the needs of the elderly and the disabled, establishing a series of requisites with regard to standardisation, in order to guarantee the access to the information society for these persons. The promotion of this principle will also lead to the development of technologies, goods and services to which many users will be able to have access.

At the present time **no data is available.**

VI.d The role of Families

Social integration of disabled persons involves also the familiar context in which they are living in. In fact, the role of the family is fundamental in many fields: from the health service to the

²⁷ European Commission, *European Day of Disabled People 1999*, on the theme “Violence and Disabled People – Root causes and Prevention”, organized by the European Disability Forum, 3rd december 1999.

rehabilitation, from the choice on the education and the work to the socialisation level. The conceptual dimensions related to the family are referable to the following questions:

- 1) In what families live disabled persons? What are their familiar roles? What are the most problematic situations?
- 2) Who are the caregivers?
- 3) What are the needs of the families with disabled persons?
- 4) Do the families with disabled persons have economic problems?

In general it is possible to calculate indicators in this field, thank to the availability of the data belonging to the NHISs (excluding indicator *f*). Some of them could be the following:

- a) Number and % of families with and without disabilities, by family composition;
- b) Mean number of weekly hours spent in aid to disabled relative, by familiar role of the caregiver;
- c) Number and % of families in poverty, by disability composition;
- d) Number and % of families covered by social protection measures, by disability composition and type of protection measures.
- e) Percentage of disabled persons requiring assistance for housework who receive it.
- f) Homeless rates among disabled persons (excluding institutionalized populations)

VII. DESCRIPTION OF THE AVAILABLE DATA SOURCES

National Health Interview Surveys (NHIS)

Surveys on the health of the population are carried out periodically in the majority of the EU Member States. However, only a small number of surveys are carried out on a yearly basis, whereas the majority of them have longer intervals (from 2 to 10 years). Many other surveys have been carried out only once.

The collection methodology varies from survey to survey. The topics which are more frequently covered by such surveys are: health status, as perceived health, chronic conditions, physical disability and activity limitations; health protection, including subjects such as hospitalisation, medical examinations and drug use; life styles, referring to subjects such as diet, aptitude towards health promotion, the awareness of health campaigns, personal hygiene, exposures to risk factors.

The National Health Interview Surveys are probably the most important sources, but with the following limits:

- 1) almost all NHIS do not include disabled persons in institutions, and/or disabled children. In this case it should be necessary to consider other data sources in order to obtain an information as much complete as possible (e.s. Austria and France have ad-hoc survey on disabled persons in institution; in Italy, at the current time, a survey on Social Assistance Services is being carried out and it is expected that an estimation of disabled persons in institution will be available).
- 2) the second problem concerns the population whom the questions regarding the ADL (Activities of Daily Living) are directed to. In fact, the starting age for filling up the questionnaire by disabled persons within the MS is much different (e.g. 6 and over, 55 and over, 65 and over..).

Moreover, many difficulties are the result of both the use of different terms and phraseologies for referring to the same concept, and the use of different measuring systems.

These wide differences and difficulties clarifies the reason why this data source has to be completed and integrated with the help of other available administrative sources.

Obviously these differences influence data comparability that is often scarce²⁸. Comparability is higher for those questions concerning the prevalence of specific diseases, chronic conditions of co-morbidity, perceived health; it is extremely good for anthropometrical measures; on the contrary, it is rather scarce as to hospitalisation, medical examinations, exposures to smoke and alcohol.

Most of the surveys contain questions on different aspects of disability. Overall comparability is low between surveys and no survey could be compared on all or most questions. However, there are 6-8 surveys asking similar questions and may be to some extent comparable²⁹.

Administrative Data of National Health Services

These are administrative data referred to the offer and the use of health services. Such data are contained in the collection of administrative data on health of all the EU countries. Among such data, those on hospital activity and particularly those on hospitalisation - recorded on specific cards have to be mentioned. Many data coming from health services (on structures and expenditure) are used - at international level - by WHO and OECD for health statistics currently produced. A significant contribution to the comparability of such data is given by the EUCOMP project financed by the European Commission³⁰. The main aim of this project is to build a European system of standardised descriptions and comparison of the different health systems so as to lay the foundations for a system of common health statistics at EU level. Therefore, the product of this project is aimed at the creation of a data structure and a comparison tool which may be applied both to all Member States and at International level. This should lead to an harmonisation and rationalisation of the data flow, to a better-defined information on health data in the EU countries as well as to the production of more appropriate indicators. The project is based on the International classification for health as presented in the recent OECD works and makes use of the guidelines for the gathering of data related to the WHO – HFA and OECD databases.

Health for all Statistical database – WHO

It contains health statistics of countries of the WHO European Region. In particular, there are various indicators conceived in order to monitoring the policies of the Health for All³¹ concerning the health status of the population (mortality, morbidity, disability), its determinants (life styles, environment, health assistance) as well as a background of demographic and socio-economic indicators. Such indicators are obtained by different sources and sometimes their comparability among countries is limited. However, they cover many aspects of the European health and represent a good basis for the calculation of complex indicators.

Eurobarometer

The traditional Standard Eurobarometer (EB - established in 1973) consists in about 1,000 representative face-to-face interviews per member country carried out between 2 and 5 times per year with reports published twice yearly. In-depth studies are carried out for various services of DG Education and Culture (on their behalf and account) and likewise for any DG of the Commission needing them, as well as for other EU institutions (if and when they so wish, as Parliament regularly does).

The Flash Eurobarometers are conducted, by phone, throughout the EU if and when needed by service of the Commission or other institutions/agencies of the EU. Possibilities are numerous:

²⁸ C. Hupkens, Coverage of health topics by surveys in the EU, EUROSTAT Working Paper 1997; C.Gudex and G. Lafortune, An Inventory of Health and Disability – Related surveys in OECD Countries", 2000;

²⁹ EUROSTAT, Task Force on "Health and Health Related Survey Data", Eurostat Disability *Project A: Survey Data On Disability*, prepared by: Claire Gudex, Stine Hvitved Christensen & Niels Rasmussen, National Institute of Public Health, Copenhagen (DK).

³⁰ EUCOMP – Towards Comparable Health Care Data in the European Union, Parts 1-3, 2000

³¹ WHO, *Health for All Programme*, 2000.

interview techniques, variable sample size, "special target groups" (e.g. teachers, managers, opinion leaders, etc.) or "public at large" studies. Here again, it is the responsibility of the respective services to release their results.

Recent Eurobarometers surveys conducted in the field of health are: Europeans, health, and the healthcare system (4-5/98); Europeans and cancer (4-5/98); Women and breast cancer (4-6/99); Europeans and health and safety in the work place (4-5/96).

OECD Health Data

These are annual statistics that OECD gathers in 29 countries, among which the EU Member States. There are about 1,000 series of data concerning key aspects related to the health system in different countries chosen so as to be easily comparable among the various countries. Furthermore, they contain a series of indicators on the health status and the quality of assistance, as well as the current trends on the health status in the OECD countries together with economic data on health expense and on non-monetary indicators of resources, input and results of the health systems.

OECD and the Data Collection Instrument on "Special Needs Education"

This data collection instrument was developed in the autumn of 1996 and through 1997, within the Project on "Special Needs education", starting from the already existing UOE data collection exercise (UNESCO/OECD/EUROSTAT), where the data relating to special educational needs were restricted to the students in special schools, giving only a partial picture of the extent of provision for students with special needs. "The central concern of the study has been the development of a data collection instrument, with the end product specified as a joint UNESCO/OECD/EUROSTAT recommendation to data providers to include the data collection instrument in the UOE data collection. It was seen as crucial that this central concern was kept firmly in mind throughout the study"³².

European System of integrated Social PROtection Statistics (ESSPROS)

The ESSPROS was developed during the 1970s by EUROSTAT with the Member States of the European Union. It consists of a stable, annually collected set of data on the receipts and expenditures of social protection schemes in the European Union.

The aim of ESSPROS is "to provide a comprehensive, realistic and coherent description of social protection in the Member States:

- covering social benefits and their financing;
- geared to international comparability;
- harmonising with other statistics, particularly the national accounts, in its main concepts"³³.

The risks or needs that may give rise to social protection are fixed by convention as follows: sickness, health care, disability, old age, survivors, family, children, unemployment, housing, and social exclusion not elsewhere classified.

European Community Household Panel (ECHP)

The European Community Household Panel, introduced in 1994, is a multiple-purpose longitudinal survey, launched within the framework of the ESS (European Statistics System) as an instrument for the monitoring of the phenomena concerning various social matters.

³² OECD, *Special Needs Education*", pg.12, 2000

³³ Eurostat, ESSPROS MANUAL; 1996

In the first wave (in 1994) a sample of 60,500 households was selected and interviewed (approximately 130,000 adults aged 16 years and over).

In the ECHP a central place in the development of comparable social statistics across Member States is given by some issues such as: income (including social transfers), labour, poverty and social exclusion, housing, and health.

Data are collected by “National Data Collections Units”, either National Statistical Institutes or research centres of the following countries: Belgium, Denmark, France, Germany, United Kingdom, Greece, Ireland, Italy, Luxembourg, Holland, Portugal, Spain (from the first wave), Austria (that joined the survey in the 1995) and Finland (that joined in 1996).

The weakness of the ECHP data is due to the modest size of the sample, to the differences in the concepts and definitions used in the national and international policies, and finally in the low answering rates matched in some countries.

Facing the necessity of referring to this data source for the calculation of some indicators identified within different thematic areas, it was considered opportune to proceed to a validation of the ECHP data, based on the comparison between the data on disabled persons coming from ECHP and those coming from the NHIS. It was possible due to the high percentage of answers that Italian ECHP collected (about 95%). The validation started from the comparison of both the population of disabled people identified within the NHIS and the ECHP, in order to verify the robustness of ECHP data. The results of this first comparison were encouraging, in fact the percentage of disabled persons on total population identified within these two data sources is quite the same. However, on a more accurate analysis, the characteristics of both populations are not completely the same: in fact when it was proceeded to a stratification for age groups some differences became evident. Anyway, these differences are not so wide to justify the choice to abandon the ECHP as a complementary source of the Italian NHIS. The comparisons have been done also with regard to the occupational condition and the educational level.

For this reason it was agreed to include the ECHP among the data sources of the list of the indicators identified within this document.

LFS (Labour Force Survey)

The LFS is the most important source for the monitoring of the labour market at a National and at European level. All the main statistics related to the labour market and comparable among the MS are due to this sampling survey. But at the current time no data on disabled persons are available in this survey: in fact it includes only general information about those unable to work. Anyway, a project of the European Commission is being carried out for including within this survey an ad-hoc module on disability, during the year 2002, that will permit to collect a broad range of information on disabled persons and the labour market.

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